

# Environment and participation of adolescents with autism spectrum disorder

## Citation for published version (APA):

Krieger, B. (2022). *Environment and participation of adolescents with autism spectrum disorder: a multi-perspective study*. [Doctoral Thesis, Maastricht University]. Maastricht University.  
<https://doi.org/10.26481/dis.20220913bk>

## Document status and date:

Published: 01/01/2022

## DOI:

[10.26481/dis.20220913bk](https://doi.org/10.26481/dis.20220913bk)

## Document Version:

Publisher's PDF, also known as Version of record

## Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
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A photograph of a spiral staircase with a metal railing, winding upwards. The background is a sky with soft, colorful clouds in shades of blue, pink, and orange, suggesting a sunset or sunrise. The staircase is made of dark metal and has a modern, industrial feel.

# **Environment and Participation of Adolescents with Autism Spectrum Disorder**

**Beate Krieger**

**A multi-perspective study**

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Layout: Tiny Wouters

Cover design: Beate Krieger

Production: ProefschriftMaken.nl

The studies presented in this dissertation were supported partly by “Ergostiftung Zurich” and “Kindertherapie Stäfa”

ISBN: 978-94-6423-884-6

# Environment and participation in adolescents with autism spectrum disorder - a multi-perspective study

Dissertation

to obtain the degree of Doctor at the Maastricht University,  
on the authority of the Rector Magnificus,  
Prof.dr. Pamela Habibović  
in accordance with the decision of the Board of Deans,  
to be defended in public  
on Tuesday 13<sup>th</sup> .of September 2022, at 13.00 hours

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The research presented in this thesis was conducted at CAPHRI Care and Public Health Research Institute, Department Family Medicine, Maastricht University. CAPHRI participates in the Netherlands School of Public Health and Care Research (CaRe).

*«Lass für mich ein Licht noch an,  
nach dem ich im Dunkeln suchen kann.  
Gib mir noch ein Zuhause mehr,  
damit ich wenigstens einen Teil der Welt versteh.»*

aus «Alles, nichts und beides» von Amina Abdulkadir



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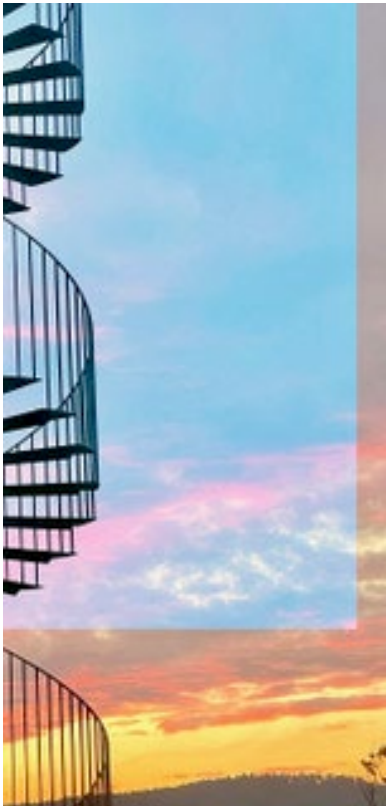
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# CHAPTER 1

General introduction





# INTRODUCTION



Foto from Marc, permission to publish perceived

## Case 1: Marc (20) university student, concert visitor, boyfriend

Marc started to enjoy attending concerts of his favorite music bands with his girlfriend. They normally enter the concert hall two hours in advance to have enough time for exploration, including examining the position of the lights, the speakers, the acoustics, and the bathroom. He knows that these concerts have light shows. To avoid artificial flashes, he closes his eyes, anticipating that there will always be a sequence of them. He loves to stand in front of the stage, equipped with ear protection and enough substitutes to manage if they break. The dense situation is acceptable because he knows that when he wants to leave, it is easy to go back, as everyone wants to move forward. He loves this shared experience with his girlfriend. He would have never made these experiences without her.



retrieved from the website of the cantonal fishing club Zürich  
<https://www.fkz.ch>

## Case 2: Phillip (15) internship, member of the local fishing club

Phillip became a member of the fishing club after attending a fishing excursion with his father, who was officially invited. Phillip loves the calmness and the clear rules that are connected with fishing. He is part of the active youth section, and his mother helps him to get organized and attend the fishing sessions. The trainer is the only person he communicates with regularly. Although he hates dirt and mud, Phillip understands that it is part of members' duties to clean a local lake once a year. Since he once found an old bike in a muddy puddle, he is convinced of how important this activity is. Phillip attends annual club membership meetings with his parents, who became passive members of the club as well.



retrieved from <https://de.vecteezy.com/vektorkunst/2919245>

## Case 3: Luc (15) pupil, taekwondo practitioner

A short @message about Luc from the taekwondo trainer to members of the youth club:

«Imagine that you go into training with the thought that nobody really wants to talk to you during training. When you are telling something, nobody really listens to you. You are being ignored. As soon as a partner exercise must be done, you realise that nobody wants to train with you. Which of you would want to come to training under these circumstances and for how long? This is what Luc must struggle with every time he comes to us for training. For many of us, small things are enough to prevent us from training or stopping altogether. But not for Luc! He has never lost sight of his goal, why he comes into training and what he stands for there. Despite everything he has to experience, he has remained true to himself. We can all learn a lot from him.»

Twenty years ago, the World Health Organization (WHO) introduced the International Classification of Function, Disability and Health (ICF) and shifted the attention of rehabilitation and outcome measures away from solely examining symptoms and functions towards considering participation combined with a focus on contextual factors such as the environment (e.g. social, physical, attitudinal) as well as personal factors (e.g. age, sex, preferences).<sup>1,2</sup> An environmental focus can provide new perspectives to support participation for socially challenged persons, such as those on the autism spectrum.

The three cases above illustrate how the participation and environments of adolescents with autism spectrum disorder (ASD) are intertwined. This dissertation

elaborates the role of environments in the participation of adolescents with ASD. The gained insight will hopefully benefit adolescents with ASD and improve their participation.

## AUTISM SPECTRUM DISORDER

Over the past century, researchers and clinicians have attempted to categorize the heterogeneity of autism spectrum disorder (ASD).<sup>3</sup> By implementing the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition (DSM-V), in 2013, the American Psychiatric Association defined ASD as a spectrum diagnosis, indicating symptoms fall on a continuum, with some individuals showing mild and others more severe symptoms.<sup>4</sup> DSM-V characterizes the main diagnostic features of ASD as (1) deficits in social communication and social interaction, and (2) restricted/repetitive behaviors, interests, and activities.<sup>4</sup> Primarily diagnosed in childhood, ASD is considered to be a lifelong condition<sup>5</sup> and longitudinal outcomes are relevant for families, health services, and society.

Although ASD is diagnosed worldwide, published epidemiological data is often inconsistent due to diagnostic changes, different assessment methodologies, and diverse culturally-based constructs of autism.<sup>6,7</sup> Globally, the prevalence of ASD is estimated to be 0.62%,<sup>6</sup> while in the United States prevalence rates between 1.4% (in 8-year-old children)<sup>8</sup> and 2.5% (in current diagnosed young people between 3-17 years)<sup>9</sup> have been published. A population-based study from Britain reported that 1% of adults have ASD.<sup>10</sup> The German Diagnostic Guidelines for ASD are based on a prevalence rate of 0.9-1.1%, indicating that 1 child out of 160 is affected by ASD.<sup>11</sup>

Historically, longitudinal internationally-coordinated research has examined the major life areas of work, friendship, and independent living and research has found at least 50% of poor outcomes in adults diagnosed with ASD.<sup>12,13</sup> These poor outcomes are costly for societies from an economic perspective.<sup>14</sup> The lifetime support costs of a person with ASD in the Netherlands can illustrate societal costs depending on the outcome level. Lifetime support costs per person range from 114.500 Euro (independent living and work) to 2.6 million Euro (reduced independence, supported work and living) or even up to 4.3 million Euro (dependent living, no work).<sup>15</sup> The enormous increase in autism-related research also reflects the importance of changing outcomes. Between 2005 and 2009, a 5-fold increase in ASD research was reported.<sup>16</sup> However, not all age groups have been explored equally.

## ADOLESCENTS WITH ASD AND THEIR PARTICIPATION GAPS

This dissertation focuses on adolescents on the autism spectrum between 12 years and 21 years of age, which is an age group that is rarely addressed in autism-related research.<sup>17</sup> Adolescence comprises a transitional period of physical adjustments and role changes within the family and society.<sup>18,19</sup> Transitions often occur in outside-of-school contexts such as in the development of peer relationships, increasing mobility, greater independence, and moving into post-secondary education or work, which thus serves as preparation for adult lives.

Within the International Classification of Function, Disability and Health (ICF) ICF<sup>2</sup> and its child and youth version ICF-CY,<sup>1</sup> participation is defined as “*involvement in a life situation*”<sup>20(p7)</sup> and reflects areas of a person's overall functioning. In adolescents, participation describes how their lives are interwoven with the social life of their family, friends, and community. Participation includes feelings of belonging and engagement and a societal perspective of an individual life.<sup>21</sup> Participation comprises performing activities alone or with a social entity; the latter is referred to as “social participation.”<sup>22,23</sup>

In general, adolescents on the autism spectrum participate less frequently and are less involved than their peers without a disability in leisure activities<sup>24</sup> or sports.<sup>25,26</sup> They experience fewer peer relationships and friendships,<sup>27</sup> have more restrictions on participation within the family,<sup>28</sup> and pursue less vocational participation after leaving school.<sup>29,30</sup> Moreover, adolescents with ASD present with greater loneliness than typically developing peers,<sup>31</sup> are bullied more often,<sup>32</sup> and commonly have social anxiety.<sup>33</sup> Further, a high suicide rate is reported due to different communication patterns and more internalized behavior.<sup>34</sup> As a consequence, adolescents with ASD participate less at home, at school, and in the community, and transitioning into adulthood poses huge challenges.<sup>18</sup>

It can be expected, that intensifying adolescents’ participation will lead to more satisfactory participation in adulthood.<sup>35,36</sup> To achieve higher social participation in adults with ASD, researchers found environmental support characteristics (such as social networks or informal support) were more important than disability characteristics.<sup>37</sup> Similar effects have been reported in young children with ASD.<sup>38</sup> Experts judged 39% of all participation support as being environmental. Environmental



characteristics are theoretically changeable and may be an important entry point for intervention.<sup>13</sup> To our knowledge, the role of the environment in the participation of adolescents with ASD has been little researched.

## THE ROLE OF ENVIRONMENT IN GENERAL AND PARTICULARLY WITH PARENTS

The disability report of the World Health Organization (WHO) demands a clearer understanding of people's environments.<sup>39</sup> It assumes that understanding and measuring the environment and its impact on disability will "facilitate the identification of cost-effective environmental interventions".<sup>39p46</sup> Environments, defined in ICF as making up "*the physical, social, and attitudinal environment in which people live and conduct their lives*"<sup>2p10</sup> can support or hinder participation in a dynamic interplay.<sup>40-42</sup> The three cases mentioned above illustrate how the participation of these adolescents on the autism spectrum are inherently related to their environments: friendship, parental company, and organizing help are described as supportive social environments, while rejecting attitudes from peers or unexpected noise or light are described as hindering environments. ICF classifies environmental factors in five domains. However, the effect of these environmental factors on participation has been little researched in children with ASD<sup>43</sup> and even less in adolescents with ASD. In one of these rare studies, the authors assumed that rich community resources such as swimming pools, parks, physical programs, or transportation facilitate adolescents' engagement in more vigorous physical activities after school.<sup>25</sup> Perceived negative attitudes increase as children with ASD transition into adolescence<sup>44</sup> and may result in more social withdrawal.

However, in accordance with other researchers,<sup>21,45,46</sup> we think that an in-depth exploration of how this person-environment interplay is supportive or hindering is needed. To complement this, we chose the '*reasonable person model*' by environmental psychologists Kaplan & Kaplan (2009, 2003), which describes environment-person interaction qualitatively.<sup>47,48</sup> It provides a clear definition of '*supportive environments*,' which address the human desires to explore, understand, enhance competence, be part of a solution, and participate with others in the pursuit of meaningful goals.<sup>47,48</sup> Further, it stresses the reciprocal aspect of the person-environment interplay by examining restorative and healthy environments. For

example, subjective relevant information is seen as an environmental requirement to feel relaxed and restored.

In particular, parents and families are seen as playing the most critical role in the environment in childhood.<sup>49</sup> While less dependence on parents is assumed in adolescence,<sup>46</sup> parents are still extensively involved in the lives of adolescents with ASD, which illustrates this interplay (others call it a “transactional relationship”<sup>50</sup>) perfectly: parents are not only the best-informed people regarding their children, but they are part of and actively create their children’s immediate social and physical environments at home. They further influence environments and contexts at school and in the community to a significant extent.<sup>51</sup> There is emerging scientific evidence that, within their caring function, parents play an important environmental role in the participation of adolescents with ASD. Examining three environmental factors respectively, (1) the number of services, (2) greater maternal participation in social and recreational activities, and (3) inclusion while in school were all strongly positively correlated with the participation of adolescents with ASD.<sup>52p251</sup> Lasgaard and colleagues<sup>53</sup> found that while adolescents with ASD were lonelier than a control group, perceived social support from family, peers, or friends was protective against loneliness. It has also been noted that adults play an active role in supporting the friendships of their children with ASD.<sup>51</sup> However, although parents have recently been included in the entire service process for children and adolescents with ASD, visible in areas such as diagnostics,<sup>54</sup> shared decision making,<sup>55</sup> or the delivery of family-centered care,<sup>56</sup> it is still unknown how we might understand their perspective on the participation of adolescents with ASD within their double role as being important to social environments themselves and at the same time creating an environment for their children to a significant extent. Through enhancing the environmentally focused role of parents we can strengthen the mandate to prioritize intervention outcomes for their children, themselves, and their families, as well as help them be involved in outcome measure reporting.<sup>57,58</sup> Thus, the proposed research will put adolescents with ASD and their parents and families at the center of the inquiries.

## PROBLEM STATEMENT

To summarize, the often-reported low participation rate in adolescents with ASD<sup>24,27,59</sup> is problematic for adolescents themselves, their immediate families, their

communities, and society, due to the immediate and long-term consequences to their well-being and functioning.<sup>13,60</sup>

The supporting and hindering role of environments in the participation of adolescents on the autism spectrum is to our knowledge fragmentized and rarely researched.<sup>17</sup> As captured by the ICF, only the entire width of environments can provide a complete picture. Negative consequences of this fragmentation include missed opportunities to support the participation of adolescents with ASD and to remove hindrances. The magnitude of this missing opportunity cannot be reported yet, but generally, in youth with disabilities, environmental factors such as social support or available services are estimated to explain between 50% and 64% of the variation in participation frequency and involvement.<sup>61</sup>

Moreover, insight from adolescents on the autism spectrum themselves (and, to a minor extent, their parents) with respect to supporting and hindering environments for their participation is rare. At the beginning of this dissertation, we only knew of three international papers describing the perspectives of adolescents with ASD on participation and environments.<sup>51,62,63</sup> With regards to the transactional aspect of participation, which *“occurs at the intersection of what the person can do, wants to do, has the opportunity to do, and is not prevented from doing,”*<sup>50p29</sup> insider and outsider views such as those of adolescents with ASD and their parents must be considered for any description or measurement of participation and environments.<sup>64</sup>

## AIMS, RESEARCH QUESTIONS, AND OBJECTIVES

This research aimed to deepen our understanding of the role of environments as supportive or hindering to the participation of adolescents with autism spectrum disorder.

Two subsequent research questions guided the entire thesis:

1. What is the role of environments as supportive or hindering to the participation of adolescents with ASD as described in the literature and by adolescents themselves?
2. How do parents of adolescents with ASD perceive and describe the role of environments as supportive or hindering to the participation of these youth?

## SWITZERLAND AS CONTEXT FOR THIS RESEARCH

The context of the empirical part of this research will be the German-speaking part of Switzerland. Switzerland provides a relatively stable, secure, and well-defined environment for all residents. It provides a high quality of life, as well as an economically prosperous and multi-cultural setting.<sup>65</sup> Public transport functions well and it aims to achieve equal accessibility for all. The social health system covers almost all of the costs of children's education and therapy. Swiss authorities assume 1% of the population are on the autism spectrum.<sup>66</sup> After signing the Salamanca declaration on inclusion,<sup>67</sup> the majority of adolescents with ASD in the canton of Zürich attend public school and live at home.<sup>68</sup>

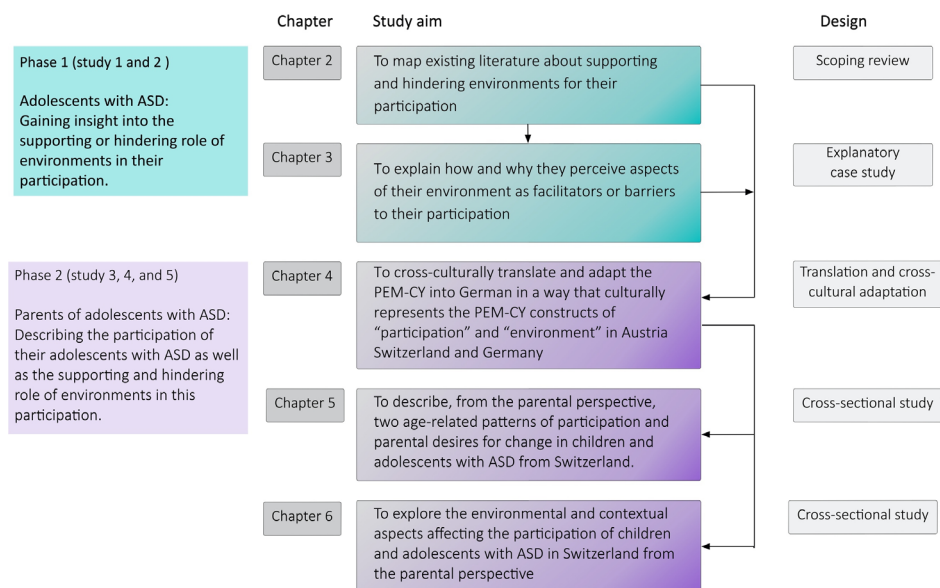
Considering the legal age of adulthood, we deliberately included early, middle, and late adolescence and thus covered adolescents between 12 and 21 years of age for two Swiss-specific reasons: first, 21 years is a cut-off age for supportive medical treatment from the federal social insurance office for persons with early-onset autism (according to the International Classification of Diseases (ICD) version-10). Second, this allows us to cover the vocational transitions of adolescents with ASD, which start in Switzerland with an apprenticeship around the age of 16.

Data about the participation of adolescents in Switzerland are rare, since internationally used measurements for participation and environment<sup>69,70</sup> are rarely translated and culturally adapted to the languages used in Switzerland.<sup>71</sup> To date, only one survey has looked epidemiologically at the participation areas of youth with ASD outside schools.<sup>72</sup> Out of 481 families, 86% of persons with ASD live with their families. 46% of youth attend inclusive schooling. After obligatory education (finishing after nine years), 35% of adolescents attended high school, 24% started an apprenticeship, and 35% entered sheltered workplaces.<sup>72</sup> Preferred leisure activities were 76% joint family activities, 60% films or computer games, 34% sport, and 21% socializing with friends. Close family members were the main social partners of 97% of all participants, followed by broader family (56%), schoolmates (31%), and community contacts (24%). Further environmentally based research from Switzerland or research involving the perspectives of adolescents with ASD or their parents is to my knowledge nonexistent. Therefore, choosing Switzerland and Zurich (when a concrete context is needed) will contribute to the novelty of this research.

## DISSERTATION OUTLINE

This dissertation presents the subsequently performed five studies in two phases, as outlined in Figure 1.1. In the first phase, the role of environments as supporting and hindering for the participation of adolescents with ASD is elaborated. In the second phase, their participation and environments from the perspectives of parents are elaborated further.

**Figure 1.1** General outline dissertation



**Chapter 2** presents a scoping review for which the ICF served as the guiding framework for inclusion/exclusion during the selection of the literature and thematic analysis process. **Chapter 3** outlines an explanatory case study from the region of Zurich. In-depth interviews with six adolescents on the autism spectrum and photos taken by the participants during activities outside of home and school were analyzed. **Chapter 4** recounts the translation and cultural adaptation of an assessment measure, the Participation and Environment Measure for Children and Youth (PEM-CY), into German. Parents of children and adolescents with disabilities from three German-speaking countries participated in think-aloud interviews. This German version (PEM-CY(G)) was used for the studies described in the following two chapters. **Chapter 5** presents a cross-sectional study describing from the parental perspective two age-related



patterns of participation and parental desires for change in 60 children and 55 adolescents with ASD in Switzerland. **Chapter 6** uses data from the same cross-sectional study but presents parental perspectives on supportive or hindering environments in combination with the contextual strategies parents applied to improve their children's participation. **Chapter 7** summarizes the main findings of the thesis and discusses theoretical aspects, methodology, recommendations, and the conclusions of the thesis. **Chapter 8** contains a summary in English, German, and Dutch. **Chapter 9** presents in layman's terms the impact of this thesis on research, teaching, and practice. **Chapter 10** contains an addendum.

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# CHAPTER 2

Supporting and hindering environments for  
participation of adolescents diagnosed with autism  
spectrum disorder: a scoping review



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*PLoS One.* 2018; 13(8): e0202071

## ABSTRACT

The influence of a person's environment and its modifying potential on participation is well recognized for most childhood disabilities, but scarcely studied for adolescents with autism spectrum disorder (ASD). A scoping review was conducted, the aim of which was to map the existing literature about supporting and hindering environments for the participation of adolescents with ASD. Sources of scientific evidence were searched for in four databases. Inclusion criteria were the perspectives of adolescents between 12 and 21, families, peers, or significant others; ecologic validity; and a clear connection between environment and participation. The publication dates ranged from 2001 to 2014 and partly up to 2018. The International Classification of Functioning, Disability and Health (ICF) served as the guiding framework for inclusion/exclusion during the selection process. Thematic analysis was performed by five independent reviewers. Results were additionally validated by stakeholders. This scoping review identified 5528 articles, and finally included 31 studies. Two main themes were found: "providing security" indicates how the environment, and specifically the parental, physical, and informational environments, have a securing or intimidating effect. The second theme, "helping to connect", indicates which environments support or hinder social relationships or social activities, and hence participation. An additional third main theme, "tension in participation", relates to ambiguities that seem essential to understand participation or isolation of adolescents with ASD. Results show that participation is a value-laden concept. This research widens the field of dealing with adolescents with ASD, as it directs attention towards the responsibility of the environment regarding participation.



## INTRODUCTION

At least 0.65 to 1% of the world's population is diagnosed with autism spectrum disorder (ASD).<sup>1-3</sup> According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition Disorders (DSM-5) criteria, this causes "clinically significant impairment in social, occupational, and other fields of current functioning".<sup>4(p50)</sup> Based on this diagnostic manual, medical-functional research currently predominates over the bio-psycho-social focus.<sup>2</sup> With regard to the latter, few studies have covered younger children,<sup>5</sup> or adults<sup>6</sup> with ASD, nor did they focus exclusively on adolescents with ASD.<sup>7</sup>

Adolescence is a period of physical adjustments and role changes within the family and society.<sup>8</sup> The family becomes less important. Adolescents experience transitions, often in out-of-school contexts such as peer-relationships, increasing mobility, increased independence and moving into post-secondary education or work.<sup>9</sup> For the first time, individuals intentionally build and reflect on social and occupational roles offering guidance on expected behavior and responsibilities.<sup>8</sup> While some roles are inherent, such as those of son/daughter or sibling, others such as friend, hobbyist, or professional are actively chosen. Engagement in occupational roles frequently includes social interaction with others, which is affected in adolescents with ASD. It has long since been established that adolescents have to learn patterns of actions required for participation in society as adults.<sup>10</sup> Fifty percent of adults with ASD show poor participation outcomes with regard to work, friendship and independent living.<sup>11-14</sup> Research has shown that intensifying the participation of adolescents with ASD might lead to satisfactory participation in adulthood.<sup>15-17</sup>

Adolescents with ASD participate 25% less in cooperative interactions during inclusive schooling.<sup>18</sup> They have a higher score for loneliness,<sup>19</sup> are often bullied,<sup>20</sup> and commonly experience social anxiety.<sup>21</sup> About 50% have no peer relationships outside of pre-arranged settings, and friendship level is reported to be low.<sup>22</sup> Few participate in social groups such as those engaging in recreational activities or attending religious services.<sup>22</sup> Attendance rates for postsecondary education,<sup>23</sup> and vocational participation<sup>24</sup> and community participation are reported to be low.<sup>25</sup>

The International Classification of Functioning, Disability, and Health (ICF) summarizes these situations under its bio-psycho-medical perspective as "participation", defined as "*involvement in life situations*".<sup>26(p26)</sup> Participation indicates how an adolescent's life is

interwoven with the social life of their family, friends, community and society, and includes feelings of belonging and engagement as well as a societal perspective.<sup>27</sup> Participation comprises performing activity alone or in an social entity, the latter referred to by some authors as “social participation”.<sup>28,29</sup> However, as the ICF has been widely criticized for its lack of conceptual clarity<sup>27,30–34</sup> and does not, for example, distinguish between subjectively experienced and objectively observable participation<sup>27,30–32,35</sup> we here extended the ICF definition to cover adolescents with ASD by adding “being engaged in and /or performing meaningful activities in occupational and social *roles*.” We decided to use Hart’s<sup>36</sup> participation ladder for further theoretical support. It focuses on the participation of children and adolescents in terms of shared decision processes and defines a graded ladder ranging from “manipulation” up to “shared decision making with adults”. Due to the weaknesses of their social interaction and communication, adolescents with ASD may be at special risk for being patronized, resulting in less shared decision-making.

According to ICF, participation is shaped and influenced by environments, defined as making up *“the physical, social, and attitudinal environment in which people live and conduct their lives”*.<sup>26(p10)</sup> Environments can support or hinder participation in a dynamic interplay.<sup>30,37</sup> Introduced as a classification, ICF lacks an in-depth view on how this interplay is conceptualized.<sup>34,38</sup> Kaplan’s “reasonable person model” stresses the reciprocal aspects of person-environment interaction.<sup>39,40</sup> From the point of view of environmental psychology, it describes supporting environments as those addressing the human desires to explore, understand, enhance competence, be part of a solution, and participate with others towards meaningful goals. These desires are especially appropriate for the phase of adolescence. Hindering environments prevent persons, in this case adolescents with ASD, from participation.

Among children and young people with disability, environmental factors like social support or available services generally explain between 50% and 64% of the variations in participation frequency and in-depth involvement.<sup>41</sup> Research has identified the mediating role of the environment as it affects the participation of children with disability.<sup>41–43</sup> As regards participation in the community by children with disabilities, the most common facilitators found were social support by family and friends and geographical factors (location)<sup>44</sup> while the most common barriers included attitudes, physical environment, transportation, policies and lack of support from staff and service

providers. Environment is also inherent in activity settings,<sup>45</sup> which for adolescents include not only their home or school, but also public spaces, sports facilities or social media.

In the field of autism, however, this role of the environment has hardly been researched. A linking study aiming to develop an ICF core set for children and young people with autism extracted 1200 meaningful concepts from the literature.<sup>7</sup> Of these, only 41 were assigned to the domain of environmental factors, compared to 1131 in the activity and participation domains. Combined with the relative paucity of research in autism focusing on adolescence, this indicates a knowledge gap. Adolescents with ASD are exposed to a range of different and often unknown environments, due to necessary developmental transitions. Yet it is not known what environments support or hinder these transitions and participation in general. From the perspective of economics, any poor outcome for persons with ASD is socially counterproductive.<sup>46</sup> More information about the environment and participation is relevant for professionals who work with adolescents with ASD, as it can help them establish environments supporting participation or remove those hindering participation. Service managers can build on this knowledge to configure public services to the participation needs of adolescents with ASD.

The aim of this scoping review was therefore to map the existing literature about supporting and hindering environments for the participation of adolescents with ASD.

## METHOD

A scoping review methodology was applied<sup>47,48</sup> to map the available knowledge on a topic which covers multiple disciplines, and to identify key concepts, gaps in research, and sources of evidence in order to inform practice, policy making, and research.<sup>49</sup> Unlike a systematic review, a scoping review identifies the entire relevant scope of the literature, regardless of study design and methodological quality of the included studies<sup>47,50</sup> and is recommended when the research focus is broader. We used the five stages proposed by Arksey & O'Malley,<sup>47</sup> and combined them with enhanced methodological rigor and the joint efforts of multiple reviewers, as recommended in different publications on the methodology for scoping reviews.<sup>48-51</sup>

## STAGE 1: IDENTIFY THE RESEARCH QUESTION

The following question was formulated: What is known in the scientific literature about the way environments support or hinder the participation of adolescents with ASD? We deliberately included early, middle and late adolescence, and so cover adolescents between 12 and 21 years of age, as there are differences in the legal age of adulthood in different countries.

## STAGE 2: IDENTIFY RELEVANT STUDIES

The Scopus, Web of Science, Cinahl, and PsycINFO databases were systematically searched, concentrating on empirical studies, secondary reviews, or dissertations. Articles were limited to those published in English in peer-reviewed journals between 2001 and 2014, to include the publication date of ICF. Five main key terms, viz. adolescents, ASD, participation, environment, and influence, were comprehensively searched for. In the past two decades, there have been many changes to the way individuals with autism spectrum disorder are diagnosed. The present research is based on the 2013 DSM-5<sup>4</sup> criteria. As previous editions used different criteria and subgroups, we also included DSM-4<sup>52</sup> and ICD-10<sup>53</sup> diagnostic terms to cover the whole historical spectrum of autism and regionally different diagnostic manuals. Additionally, terminology from the ICF classification<sup>26</sup> and the theoretical framework<sup>39,40</sup> generated broadening terms (Table 2.1).

**Table 2.1** Search strategy.

Main search terms	Additional broadening search terms <sup>1</sup>
adolescent*	youth, young adult*, student*, user*, pupil*, child*, teenager, adulthood
autism spectrum disorder*	autis*, ASD, Asperger syndrome, high function* autism (HFA), pervasive developmental disorder (PDD) "childhood disintegrated disorder", Rett syndrome
participation	involve*, "life situation", daily activit*, tasks, social competen*, communication, relationship, commun*, mobil*, "human need*", engag*, "meaningful acti*", "human acti*", integration, inclusi*,
environment*	technology, "built environment", "physical environment", "social environment", attitude, system, services, policies, context, "informational needs", restoration, ecology, setting, ambient*, cultur*
influence*	impact, relat*, effect*,

\*used with asterisk; <sup>1</sup>based based on DSM-4 and ICD-10 criteria, ICF terminology and the reasonable person model by Kaplan et al.<sup>39,40</sup>

These were truncated, exploded, and adjusted to enable comprehensive coverage, as emphasized in scoping methodology.<sup>48</sup> The first author performed the search and

documented the results by using Endnote® or Mendeley® as a data management tool. This facilitated merging double hits and reading the abstracts.

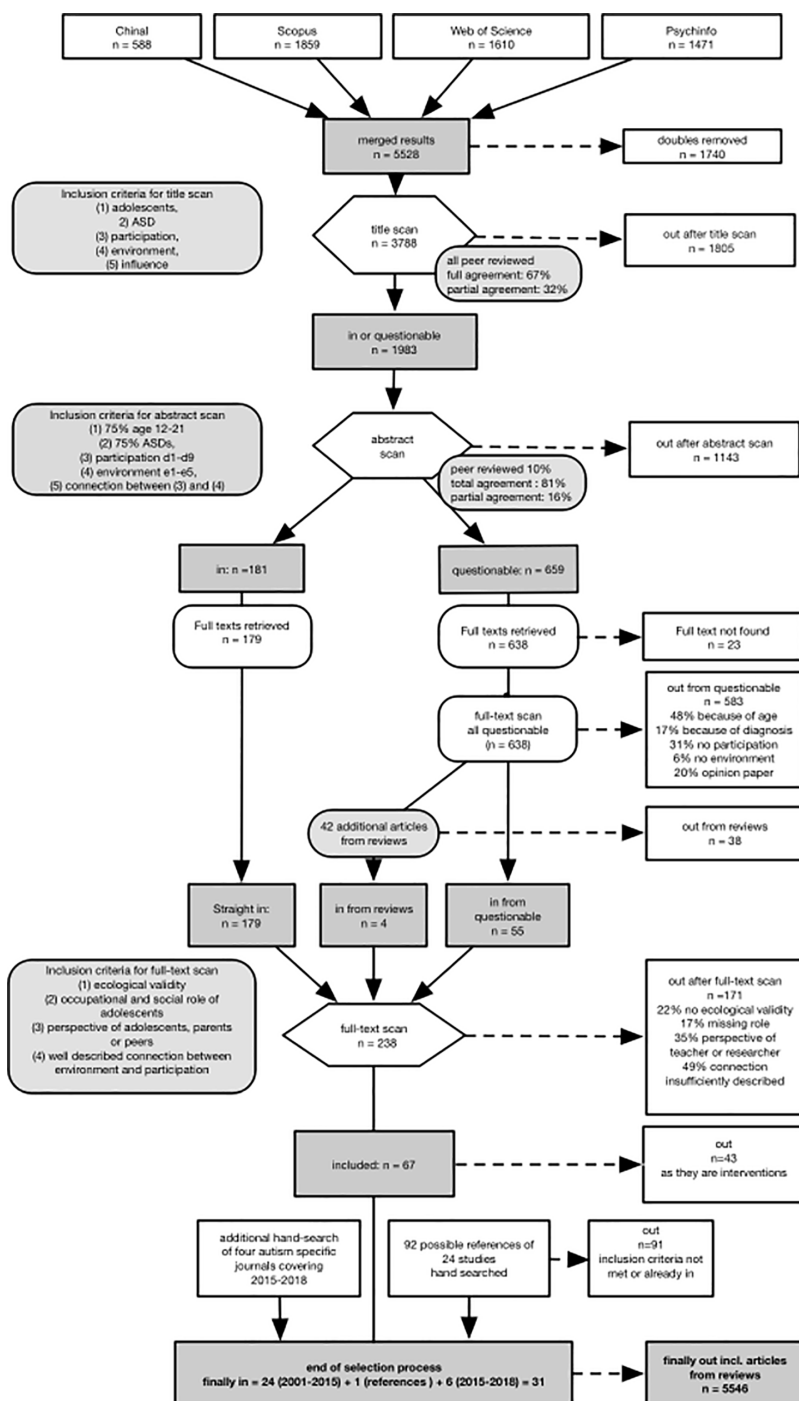
An additional hand search in four autism-related journals (Autism Research, the Journal of Autism and Developmental Disorders, Autism, and Research in Autism Spectrum Disorders) was carried out for the years 2015-2018.

### STAGE 3: SELECT STUDIES

A peer-reviewed three-step selection procedure<sup>47</sup> based on title, abstract, and full-text levels was conducted, using inclusion/exclusion criteria. As the scoping review process is iterative, the researchers reflected on, defined, and re-defined the inclusion criteria post-hoc<sup>51</sup> after re-examining them. The final inclusion criteria for each of the three steps are presented in detail in the visual flowchart in Figure 2.1, as well as the reasons for exclusion. Each step graded the article as “in”, “questionable” or “out”. Studies graded as “in” or “questionable” were taken along to the next selection step.

After eliminating any doubles, the remaining titles were scanned (step 1) to see whether they addressed each of the five key aspects (adolescents, ASD, participation, environment, and influence). During the selection at abstract level (step 2), abstracts were included if (1) at least 75% of the study sample were adolescents between 12 and 21, (2) at least 75% had been diagnosed with ASD or all subordinate ICD-10 diagnoses, (3) the study focused on participation aspects included in ICF domains d1-d9, (4) the study described environmental factors included in ICF domains e1-e5, and (5) the article indicated any connections between these particular aspects of participation and environmental factors. Studies focusing on neurobiological, genetic, epigenetic, or pharmaceutical aspects were excluded, as well as those that were theoretical or descriptive in nature, or focused on functions (e.g. processing information) or personal factors (e.g. motivation). After retrieval of full texts, those graded in the abstract scan as “questionable” were re-scanned according to the abstract scanning criteria. In the case of reviews, all reviewed articles were scanned individually using the inclusion/exclusion criteria.

Figure 2.1 Flowchart of the selection process.



Finally, the first author read all remaining full-text articles, and applied the following agreed-on inclusion criteria for the full-text scan: (1) studies had to present ecological validity, i.e. the degree to which conditions used in the study are similar to those that would occur naturally;<sup>50</sup> (2) the aspect of occupational and/or social roles had to be included, and (3) studies had to include the perspectives of adolescents, their parents, or peers; and (4) there had to be a clear connection between participation and environment according to the definition established in advance. In some cases, the perspective of the adolescents could not be examined, (e.g. in nonverbal adolescents), and studies combining observations and parental perceptions were included to maintain a comprehensive scope. Studies purely involving observations by researchers or teachers were excluded. At the end of the selection process, reference lists of included studies were hand-scanned.

Procedural rigor<sup>47,48</sup> was secured by having the first author perform all the above steps. All co-authors (AM, BP, AB, CS, UJ) validated this process. The rates of agreement based on the title and the abstract scans are presented in Figure 2.1. When disagreement occurred, the titles were taken to the next step. Finally, the core team defined the inclusion criteria for the full text scan, and decided together if connections between participation and environment in real-world settings were clearly described.

#### STAGE 4: CHARTING AND ANALYZING THE DATA

The data were charted using inductive thematic analysis.<sup>47,48</sup> According to Levraç and colleagues,<sup>48</sup> *“thematic analysis requires additional description to assist authors in understanding and completing this step”* (p 8) and resembles qualitative data analysis techniques. Specifically, we extracted parts of sentences from the selected studies as described by Yoffe & Yardly.<sup>54</sup> These served as meaningful coding units if they expressed “participation”, “supporting environments”, or “hindering environments”. Eight studies were charted by all co-authors, resulting in a 50% agreement rate. Analysis of the differences, mostly in allocating coding units to “participation” or “environment”, helped to refine the definitions. Finally, 592 coding units (248 relating to participation; 194 to supportive environment; and 150 to hindering environment) were merged and mapped into themes and subthemes. All subthemes were defined separately and supported with quotes, which were subsequently reviewed and agreed on by the core team. Additionally, some of the analysis and development of themes was performed together with two co-authors (CS; UJ).

## STAGE 5: SUMMARIZING AND REPORTING THE RESULTS

Results are presented descriptively and narratively in the Results section below.

## STAGE 6: CONSULTATIONS: VALIDATING WITH STAKEHOLDERS

Consultations with relevant stakeholders are recommended to increase the rigor of scoping reviews.<sup>47,48</sup> Yet, descriptions of how to do this are generally vague. The authors presented the emerging results to three groups of stakeholders in connection with this research: adolescents and young adults with ASD, parents and professionals. Seven persons were asked whether the results reflected their experiences, if they disagreed or whether any aspects were missing. The findings are reported in the Results section.

# RESULTS

## SUMMARY OF SELECTED STUDIES

The scoping selection process started with 5528 studies being retrieved from databases, 31 of which met the inclusion criteria. All 31 articles are listed in Table 2.2, indicating numbers of participants, research questions, methodology used, social roles, activities, and environment identified, and the main results. Column three provides information about combined intellectual disability as described in the studies.



Table 2.2 Matrix of included studies.

Author <sup>1</sup>	N <sup>2</sup>	ID <sup>3</sup>	Aims	Design <sup>4</sup>	Participation Role	Meaningful activity	Environment ICF domains	Main results
Andrews (2014) AU	214 (f)	S	To describe the relationships between impairment and contextual factors and community participation for girls and women with Rett syndrome.	Quantitative research Parents and carers (n=214) Questionnaires	leisure user community service user	Recreational, physical, skill-based social, or self-improvement activities	e1-e5 mobility, residential area, education of parents, community services, available time of parents	The frequency of participation in community activities by girls and women with Rett syndrome was influenced by factors including age, level of mobility, maternal education and degree of community support.
Amell (2018) SE	24 (m: 17) (f:7)	N	To describe how adolescents with ASD perceive, experience, and reflect on their participation in physical activities	Qualitative research Adolescents (n=24) Interviews	leisure user	Physical activities, sports like cycling, team sport, running, swimming, gymnastics	e1, e3-e5 elements of nature, weather, social demands, relationships, attitudes	Besides intrinsic aspects of willingness, participants perceived external demands as essential for their participation. Perceived social demands were prominent, but predictability and natural conditions (weather, insects) also played a role.
Baines (2012) USA	2 (m)	N	To look at how youth with disabilities develop identities as learners through their experiences across social contexts.	Qualitative research Adolescents (n=2) Interviews/observations	students peers sons	Interactions in debating clubs, classrooms, break.	e3-e4 Social relationships, attitudes, respect	Students' stories unfolded and were influenced by disability labels across different contexts in ways that continued to shape their future life trajectories.
Bentley (2008) USA	1 (f)	S	To explore the lived experience of a child labeled as having severe disabilities, and her peers with and without disabilities, in an "inclusive" school environment.	Qualitative research Adolescent (n=1), peers (n=23), family, staff Observations/interviews	peer student friend	Communication, school activities, leisure activities, social relationship	e3-e5 social relationships, inclusive setting, attitudes, staff and services	Symbolic inclusion and inclusive pedagogical practices were found to be instinctively and effectively utilized by a child with Rett syndrome and her peers, though they were given exclusionary models by paraprofessionals, and limited opportunities for interaction.
Brewster (2010) UK	20 (m: 14) (f: 6)	N	To explore what children do in their leisure time, what they would like to do in future and what difficulties, if any, they encounter.	Qualitative research Adolescents (n=20) Focus group interviews	leisure user	Computer games, surfing the internet, television, youth clubs, dance and foreign language classes, after-school club, snooker, paintball	e1-e4 transport, peer relationships, parents, neighborhood, attitudes	Needs and challenges to achieve an active and varied life outside of school and home environments are various. Predominating are a preference for solitary activities and no inclusion in local peer groups.

Table 2.2 (continued)

Author <sup>1</sup>	N <sup>2</sup>	ID <sup>3</sup>	Aims	Design <sup>4</sup>	Participation Role	Meaningful activity	Environment ICF domains	Main results
Cox (2012) USA	123 (m: 90) (f: 33)	N	To improve understanding of the difficulties individuals with ASD experience when learning to drive.	Quantitative research Parents (n=123) Questionnaires	research driver	Driving	e1, e3, e5 technical aids, teaching programs, parental relationship, services	Learning to drive presents a substantial challenge to individuals with ASD. Parents use a variety of strategies to support the learning process.
Dixon (2013) AU	2 (m)	N	To identify the perceptions of key stakeholders within two schools regarding the transition procedures before transition to high school.	Qualitative research Adolescents (n=2), mothers (n=2), teachers (n=2) executives (n=2) Interviews	student	Participation in school camps, orienting themselves, homework, getting new friends	e2-e5 visual aids, social relationships, attitudes, services	Both schools experienced difficulties with implementing successful ongoing strategies. These difficulties were linked to the lack of collaboration among all stakeholders, including the students. In fact, there was no student voice.
Evans (2001) NZ	1 (f)	S	To describe the experiences of a girl with Rett syndrome in an inclusive school and how social relationships create meaningful contexts for individuals with limited skills	Mixed methods research Adolescent (n=1), peers, family, staff Observations/interviews/focus interviews/survey	peer friend	Communication, sharing time, doing things together, asking about preferences	e3-e5 social relationships, attitudes, services, and staff	The positive friendship experiences described did not occur spontaneously, nor were they due to social skills instruction. Instead, they were associated with observable social behavior by caregivers and peers who were extending their own repertoires to accommodate someone with a severe disability.
Giarelli (2013a) USA	13 (m: 10) (f: 3)	N	To describe the phenomenon of transition to community among adolescents and young adults with ASD.	Qualitative research Adolescents (n=13), mothers (n=13), teachers (n=5), employers (n=5) Interviews	transition to adulthood	Transitioning, seeking knowledge about one's health problems, self-determination, work, job seeking, participation in the community.	e2-e5 physical environment, social relationships, attitudes, services	The core psychosocial problem of transition into the community is to stay afloat while feeling "adrift". Adolescents, with the support of parents, teachers and sympathetic employers, used structuring, anchoring, and embarking to solve their problem.
Giarelli (2013b) USA	14 (m: 10) (f: 4)	N	To explore the perspectives of adolescents with regard to their own expectations and ideas on ways to facilitate successful transitioning.	Qualitative Research Adolescents (n=14) Telephone interviews	research transition to adulthood	Transitioning tasks and preferences	e3-e5 physical environment, social relationships, attitudes of staff, availability of services	Perceived barriers were: self-assessed behavioral problems, self-assessed associated features, other personal factors, and institutional factors. Bridges to facilitate transition were: facilities in the community, cognitive abilities, personal qualities/strengths, and mentor's qualities.

Table 2.2 (continued)

Author <sup>1</sup>	N <sup>2</sup>	ID <sup>3</sup>	Aims	Design <sup>4</sup>	Participation		Environment ICF domains	Main results
					Role	Meaningful activity		
Gregor (2018) CA	10 (m: 9) (f: 1)	N/A	To explore how social, personal, systemic, attitudinal, and familial mechanisms influence physical activity participation among Canadian adolescents with ASD	Qualitative research Parents (n=10) Interviews	leisure user	Physical activities, sports, alone or in groups	e1, e3–e5 accessibility, parental priorities, funding, attitudes, services,	Parents prioritized interventions over physical activities, which shaped interest in and experiences with physical activities. Further challenges were access to programs, lack of awareness of ASD among service providers, funding, and limited program options
Howe (2016) UK	16 (m: 12) (f: 4)	N/A	To explore how adolescents with ASD perceive sensory differences to affect their learning experiences within the classroom	Mixed-methods research Adolescents (n=16) Questionnaires Interviews	student	Learning at school, listening, concentrating	e2 physical environment	Participants reported difficulties in at least one sensory domain, with hearing affecting them the most. Content analysis revealed that sensory sensitivity affected the participant's learning and that sensory experiences were largely negative.
Humphrey (2008) UK	20 (gender un-known)	N	To explore the views and experiences of pupils with AS about mainstream education and to identify practices that facilitate or constrain learning and participation	Qualitative Research Adolescents (n=20) Interviews, diaries, drawings	pupil peer	Activities in school like communicating, interacting with peers, learning, transport to school (taxi)	e3-e4 peer relationships, social relationships attitudes	The central theme was how participants constructed their understanding of what their AS meant to them. The links between this understanding and reported difficulties with peers and teachers are described. The desire to 'fit in'.
Humphrey (2010) UK	40 (gender un-known)	N	To examine the frequency of bullying and levels of social support in pupils with ASD and two control groups. To examine the contribution of social support to the frequency of bullying.	Quantitative research Adolescents (n=40) Peers (n=80) Questionnaires	peer student	Being kicked, threatened to be hurt, being demanded to hand over money, others trying to hurt them, to break sth. or to hit them.	e3-e5 peer relationships, social relationships, attitudes, services, policies	Pupils with ASD experienced higher frequency of bullying and lower levels of social support from most interaction partners. Receiving support from classmates was the most important means of reducing the frequency of bullying.
Kuo (2011) USA	91 (m: 74) (f: 18)	M	To investigate friendship characteristics, agreement between adolescent's and parent's perceptions of the adolescents' friendships and factors that may be associated.	Quantitative research Adolescents (n=91) Parents (n=91) Questionnaires	peer friend	Eating, doing physical activities, outdoor activities, education-related activities, conversations, surfing websites, and many other activities	e3 Social relationships, friends,	Adolescents with an ASD and their parents identified different peers as the adolescent's friends. The findings also reveal similarities and differences in friendships between adolescents with an ASD and typically developing adolescents.

Table 2.2 (continued)

Author <sup>1</sup>	N <sup>2</sup>	ID <sup>3</sup>	Aims	Design <sup>4</sup>	Participation Role	Meaningful activity	Environment ICF domains	Main results
Kuo (2014) USA	91 (m: 74) (f: 18)	M	To describe how adolescents with ASD use media, with whom they spend time using media, and the association between media use and parent–child relationships and friendships.	Quantitative research Adolescents (n=91) Parents (n=91) Questionnaires	media user peer friend	Different activities in connection with media use.	e3 social relationships peers, social networks, family	They most frequently watched cartoons, played computer or video games that involved shooting, and visited websites about video games. Those who watched television with parents reported more positive parent–child relationships. Those who visited social networking websites or received emails from friends reported more positive friendships.
Liptak (2011) USA	725 (m: 595) (f: 131)	M	To describe social participation and to identify factors that affect it.	Quantitative research Parents (n=725) Questionnaires	peer student employee driver	Contact through phone calls, instant messaging, meeting friends outside organized gatherings, attending work or secondary school	e3, e5 social relationships, parents, financial resources	Although many graduated from high school and integrated into society, many became increasingly isolated and had poor rates of employment and postsecondary education. Positive effects on outcomes included the ability to communicate effectively, coming from an environment that is not impoverished, and having parents who advocate.
Locke (2010) USA	7 (m: 4) (f: 3)	N	To examine the social–emotional relationships of adolescents with autism and their typically developing classmates in a mainstream high school.	Quantitative research Adolescents (n=7) Peers (n=13) Questionnaires	friend peer student	Five domains of friendship quality, including companionship (spending time together) help, security, conflict and closeness	e3-e4 peer relationships, attitudes,	Adolescents with autism experienced significantly more loneliness than their typically developing classmates, had significantly poorer friendship quality regarding companionship and helpfulness, and had significantly lower social network status than their typically developing classmates.
Lounds Taylor (2017) USA	36 (m: 30) (f: 6)	M	To examined how social participation changed after youth with ASD exited high school. To explore the interrelations between types of activities (structured vs. unstructured activities).	Quantitative research Parents (n= 36) Questionnaires	peer friend neighbor religious service user social actor in public leisure/sports	Unstructured activities like meeting relatives, peers or friend Structured activities like attending religious services and sports	e5 attending school	Results confirm that youth with ASD might be at-risk after leaving high school – by becoming more isolated from structured social activities. Many youth maintained their levels of contact with friends, neighbors, and extended family members, youth with more internalizing symptoms appear to be at greatest risk for experiencing declines in both structured and unstructured activities.

Table 2.2 (continued)

Author <sup>1</sup>	N <sup>2</sup>	ID <sup>3</sup>	Aims	Design <sup>4</sup>	Participation		Environment ICF domains	Main results
					Role	Meaningful activity		
Muskat (2016) CA	20 (m: 17) (f: 3)	M	To understand the hospitalization experiences of children and youths with ASD, their families, and their health-care providers (HCPs) with the objective of utilizing the findings to improve hospital care for children and youths with ASD.	Qualitative research Adolescents (n=6) Parents (n=22) Heal care professionals (n = 14)	patient in a hospital	Waiting, talking with medical staff, undergoing examinations	e2-e5 relationship with medical staff, physical environment, attitudes, services	Problems in the context of health-care delivery in the hospital setting included communication and sensory challenges, and the degree of flexibility of HCPs and the hospital organization. Supportive HCPs acknowledged parents as experts; inquired about the requirements of patients with ASD and implemented strategies that accommodated the unique clinical presentation of the individual patient.
Myers (2015) USA	17/818 (m: 83%) (f: 17%)	S:30% M:27% N:41%	To examine the influence of extrinsic influences such as socioeconomic status, school location, transportation, and case management, as well as intrinsic characteristics, on social and community participation by adolescents with ASD transitioning into adulthood	Quantitative research Parents (n=N/A) Adolescents (n= N/A) Teachers (N=N/A) School administrators to (n=N/A) Questionnaires	peer leisure user public peer transitions to adulthood	Community participation, social participations	e3-e5 socioeconomic status, school location, transportation, services	Community participation was associated with factors related to family resources; household income and utilization of case management. Social participation outcomes appeared to be more associated with factors that are inherent to the individual. Individuals with ASDs rely on others to help organize community and social opportunities, putting them at higher risk of poor outcomes if there is no such advocate across the lifespan.
Orsmond (2004) USA	185 (m: 140) (f: 45)	M	To describe friendships and peer relationships in social and recreational activities. To examine predictive individual and environmental factors for this.	Quantitative Research Mothers (n= 185) Questionnaires	friend leisure user	Friendship (defined with ADI-R) leisure activities	e3-e5 peer relationships, parents, attitudes, services and inclusive schooling	No environmental factor was a significant predictor of having peer relationships. Participation in social /recreational activities was sensitive to environmental factors like services received, maternal participation in social/recreational activities, and inclusive schooling.
Orsmond (2006) USA	202 (m: 147) (f: 54)	M	To examine mother-child relationship in families of adolescents and adults with an autism spectrum disorder	Mixed methods research Mothers (n=202) Questionnaires, interviews	son daughter	Verbally expressed warmth and positive affect and gains and strains	e3 mother-child relationship	Over 90% of the mothers reported to have a warm relationship characterized by high levels of affection for their child. Alteration of social impairment does not fundamentally impair the mother-child relationship during adolescence and adulthood.

Table 2.2 (continued)

Author <sup>1</sup>	N <sup>2</sup>	ID <sup>3</sup>	Aims	Design <sup>4</sup>	Participation	Environment	Main results
					Role	Meaningful activity	ICF domains
Petalas (2013) UK	12 (m:11) (f: 1)	N	To explore the perceptions and experiences of adolescents with ASD growing up with a brother or sister without ASD	Qualitative research Adolescents (n=12) Interviews	sister brother	Interactions like shared activities, enjoyment, conflicts and identity construction	Adolescent siblings with an ASD experience a world that is much like that of typically developing siblings, but where differences may be obvious they are often reminded of their "differentness". Adolescents with AS rated their classmates' attitude towards them and their attitude to their classmates lower than typically developing adolescents. They also claimed to receive less support from classmates. The type of support correlated with their peers, attitudes towards them.
Pisula (2012) PO	25 (m: 22) (f: 3)	N	To determine how adolescents with AS perceive their social situation with peers at school, focusing on attitudes.	Quantitative Research Adolescents (n=25) Peers (n=25) Questionnaires	peer	Support, sense of security, being appreciated, readings to engage, providing help, lending money, giving feedback, aggressiveness, sociability	e3, e4 peer relationship, attitudes
Rossetti (2011) USA	2 (m: 1) (f: 1)	M	To explore the contexts and dynamics of friendships between two individuals with autism and peers without disabilities.	Qualitative research Adolescents (n=2) Peers (n= 3) Interviews	friend	Communication patterns, school activities like academic work, dancing classes, breaks and leisure activities, conversations	e3 peer relationship
Ryan (2010) UK	48 (gender un-known)	M	To focus on the emotional work parents do during participation in public places with their children with ASD	Qualitative research Parents (n=48) Interviews	social actor in public space	Eating in restaurants, buying goods in a store, attending cinema, managing public encounters	e2-e4 parental relationship, social relationships, attitudes, physical environment
Saggers (2011) AU	9 (m: 7) (f: 2)	M	To examined inclusive education practice from the perspective of the student and identify practices that facilitate and constrain learning and participation.	Qualitative research Adolescents (n=9) Interviews	student pupil peer	Academic activities, enacting friendships, relationships to teachers, supporters and peers, homework, technology use, workload	e1-e5 teaching materials, space and architecture, social relationships, attitudes, services

Table 2.2 (continued)

Author <sup>1</sup>	N <sup>2</sup>	ID <sup>3</sup>	Aims	Design <sup>4</sup>	Participation Role	Meaningful activity	Environment ICF domains	Main results
Shattuck (2011) USA	900 (m:760) (f: 140)	M	To explore the rates of participation in social activities among adolescents with an ASD compared to adolescents with other disabilities.	Quantitative research Parents (n=920) School staff (n = unknown) Questionnaires	friend volunteer sportsperson leisure user	Seeing or calling friends, f invited activities, performing volunteer services, taking lessons or classes, non-school activities, groups they belong to	e3-e5 social relationships, peer relationships, attitudes, finances,	Adolescents with an ASD were significantly more likely to never see friends out of school, or to get called and be invited to social activities. Correlates of limited social participation included low family income, impairments of conversational ability, social communication, functional cognitive skills.
Symes (2010) UK	120 (m: 29) (f: 11)	N	To investigate sociometric status, perceived levels of peer support and frequency of bullying experienced by pupils with ASD in secondary schools, compared to others	Quantitative research Adolescents (n=40) Peers (n=80) Questionnaires	peer pupil	Working and playing with partners. Experiences of bullying, experiences of support by friends	e3, e4 peer relationships, attitudes	Pupils with ASD were more likely to be rejected and less likely to be accepted by their peers, experienced higher levels of bullying, and reported lower levels of social support from classmates and friends than matched pupils with dyslexia or no special needs.
Wainescot (2008) UK	57 (m: 55) (f: 2)	N	To explore how and where pupils with AS/HFA spend their school day socially, both in and out of lessons.	Quantitative research Adolescents (n=57) Questionnaires Pedometer	student peer	Having lunch, spending breaks, socializing with peers	e2, e3, social relationships, space and architecture	Pupils with AS/HFA engaged in fewer social interactions, both in and out of lessons, spent break and lunch times inside in quieter and supervised areas, had fewer friends, were less physically active and were more often the targets of bullying than matched peers

<sup>1</sup> First author, date, country; <sup>2</sup> Number of participants and gender; <sup>3</sup> Co-occurring intellectual disability (ID) : N=ID reported M=mixed ID reported ; S=strong ID reported; <sup>4</sup> Design, participants, data collection.

Most of the studies were found in two databases simultaneously, and the majority (76%) of the articles were published after 2010. The types of journals, the countries where the studies were performed, and information about the designs is provided in Table 2.3.

**Table 2.3** Patterns of publications 2001 – 2018.

Main aspect	Distribution	n=31	%
Database	Scopus (2001-2014)	9	29
	Web of Science (2001-2014)	5	16
	Both Scopus and Web of Science (2001-2014)	6	19
	Scopus or Web of Science with either PsycINFO or Cinahl (2001-2014)	6	19
	Hand search in reference lists	1	1
	Hand search in journals of autism (2015-2018)	6	19
Publication date	2001-2009	6	19
	2010 -2014	19	61
	2015-2018	6	19
Types of journals	Disability studies	5	16
	Medical (incl. those specializing in autism)	14	45
	Educational science	9	29
	Others	3	10
Countries	United States and Canada (2 mixed)	17	54
	United Kingdom	8	26
	Australia	3	10
	Poland	1	1
	New Zealand	1	1
	Sweden	1	1
Study design	Cross-sectional or mixed design	16	52
	Qualitative design	15	48
Time-range of collected data	Current data	26	84
	Retrospective data	5	16

Table 2.4 offers more detailed information about the content of the 31 studies. Results comprise a total of 20,768 adolescents with ASD. The number of participants ranged from 1<sup>55,56</sup> to 17,818.<sup>57</sup> Of these, 81% were male and 19% female, while some did not specify gender. Low (27%), mixed (35%) and no intellectual disability (36%) were nearly evenly distributed. Of the known data (missing<sup>57</sup>), 79% was provided by parents, whereas adolescents with ASD provided 18%, and peers 7%. The majority described school settings (59%), whereas community settings (35%) and home settings (21%) were less often described. Environments as defined in the ICF classification included products and technology (11%), natural or human-made changes to the environment (10%), support and relationship (38%), attitudes (20%), and services, systems, and policy (19%). In all, 13 different social roles of adolescents with ASD were identified.



The form of participation described covered interpersonal relationships (31%), major life areas (37%), and community, social and civic life (13%), while all other ICF participation domains covered less than 2% each.

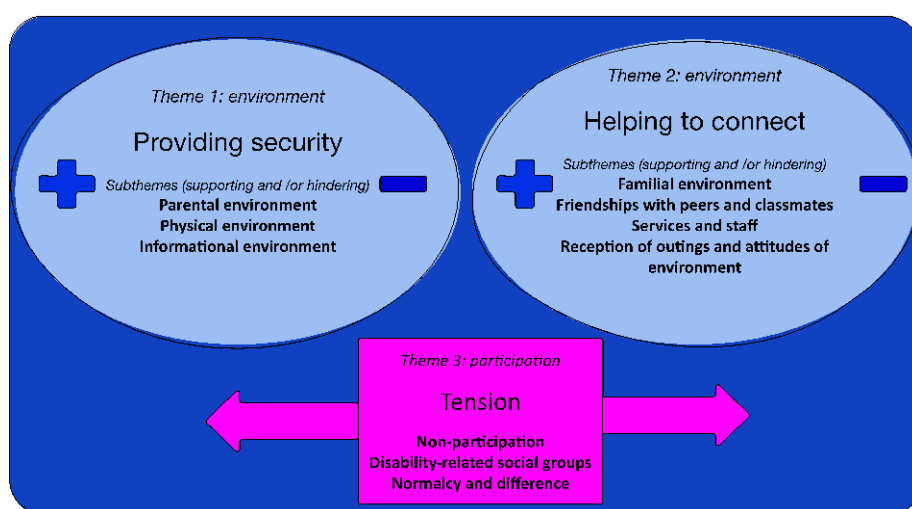
**Table 2.4** Characteristics of adolescents, environments, and participation in 31 studies.

Main aspect	Distribution	N (participants)	%
Adolescents with ASD	Total number of participants	20,768	100
	Male	16,906	81
	Female	3741	19
	Gender unknown	121	0.5
Reported intellectual disability	Strong intellectual disability reported	5667	27
	Mixed intellectual disability reported	7467	35
	No intellectual disability reported	7647	36
Informants (n=3392)	Adolescents	402	18
	Parents	2703	79
	Peers	249	7
	Others	38	1
Main aspect	Distribution	N (studies: double possible) %	
Settings (n=37)	School setting	16	59
	Home setting	8	21
	Community settings (e.g. leisure, public spaces hospital, church, work)	13	35
ICF environmental domains (n=62)	e1 (products and technology)	7	11
	e2 (natural and human-made changes)	6	10
	e3 (support and relationships)	24	38
	e4 (attitudes)	13	20
	e5 (services, systems, and policy)	12	19
Social and occupational roles (n=56)	Student/pupil	14	25
	Peer	11	20
	Friend	10	19
	Leisure participant (incl. sport)	6	10
	Public space user	4	7
	Son/daughter	2	4
	Brother/sister	1	2
	Driver	1	2
	Media user	1	2
	Employee	1	2
	Social roles in transition to work	3	5
	Religious service user	1	2
	Patient in a hospital	1	2
ICF participation domains (n=54)	d7 (interpersonal interactions and relationships)	17	31
	d8 (major life areas)	20	37
	d9 (community, social and civic life)	7	13
	d1-d6 less than 5% each	1-2 each	<2

## SUPPORTING AND HINDERING ENVIRONMENTS FOR PARTICIPATION

Thematic analysis of supporting and hindering environments for participation revealed two main themes, “providing security” and “helping to connect”. They are described here with seven subthemes (see Figure 2.2), each of which comprises supporting and hindering aspects.

**Figure 2.2** Graphic representation of supporting and hindering environments and tension in participation.



The first main theme, “**providing security**”, describes how their environment provides adolescents with personally perceived security to support their participation, or hinders it by neglecting security issues, resulting in intimidation and even fear. Three subthemes were found crucial in providing security.

The first subtheme, “parental environment”, refers to the way parents provide security and protection as a precondition for participation. The stability of a supportive relationship with parents has been described as “anchoring” when transferring to new participation areas like work, college, or new places.<sup>58–60</sup> More specifically, higher self-esteem and optimism on the part of the mother contributes to participation,<sup>58,59</sup> as it encourages taking risks and developing positive connotations about participation. Hence, the stability of the relationship with the mother during adolescence and adulthood is described as crucially important.<sup>58</sup> A further supportive aspect is when parents understand and adapt to the security needs of their children.<sup>58,60–63</sup>

Adolescents with ASD clearly expressed their preference for “safe” activities. For instance, one boy stated that he would only leave the house for communal leisure participation after his parents had checked that it was safe.<sup>62</sup> As regards the location of activities, adolescents with ASD prefer home-based activities like watching television, playing in the garden, playing computer games, or surfing the Internet. This tendency becomes even stronger as they grow older.<sup>57,62</sup> To provide security and thus support participation, it is prudent for parents to explore environments beforehand.<sup>64–66</sup> For example, they may check out a future school environment, or they can inform themselves about assisting programs for learning to drive. When parents fail to obtain this kind of information as a security function, they hinder their children’s participation.<sup>60,65</sup>

The second subtheme, “the physical environment”, refers to the impact that physical aspects of the environment, such as noise, light, smells, space, and crowdedness have on the security perception and participation of adolescents with ASD. Physical environments involving bright lights, unusual noises, darkness, crowds, queues, or unfamiliar places are often described as intimidating and overwhelming, thus as hindering participation.<sup>60,61,66–68</sup> Authors of two studies judged noise sensitivity to be the chief problem.<sup>66,69</sup> Pupils at school lose concentration, which affects learning.<sup>69</sup> In public spaces, such as during transportation, or when attending a cinema, adolescents feel offended, disrupted, and thus victimized, when they are passively exposed to the overwhelming condition of noise. In school settings, calmer spaces like libraries are reported to be preferred by adolescents with ASD.<sup>70</sup> As regards outdoor physical activities, certain elements of nature, such as insects or weather conditions, are reported as barriers,<sup>71</sup> while in hospitals, being touched frequently and hearing unusual noises are perceived as discomforting or can evoke panic.<sup>72</sup> Control of noise, but also of lighting or spaces provides security through agency. Availability of quiet areas such as school libraries, light dimmers, volume control of sound systems in public spaces, and repositioning of chairs to control space are supportive environmental conditions.<sup>59,66–68</sup>

The third subtheme, “informational environment”, addresses the comprehensibility of environments. Adolescents with ASD often report that awareness of upcoming activities, social expectations, and implicit demands are challenging.<sup>64,65,71,73,74</sup> Order and predictability are described as a “*security blanket*”,<sup>68(p35)</sup> as they mean that demands are more familiar and thus clearer. A higher participation rate has been reported for regularly scheduled and structured activities.<sup>22,75</sup> New situations, for

example when starting a new job or attending a new sports facility, are described as a source of unease and instability.<sup>66,68,71,73,76</sup> Accessible and processable information become imperative environmental conditions for participation. Knowing what to expect beforehand allows these adolescents to plan their participation and engagement in physical activities.<sup>71</sup> When understanding, interpreting, and reacting to social demands are difficult for these adolescents, they feel intimidated by their environment.<sup>66–68,77</sup> It is difficult, for example, to understand the subtleties of social interaction between peers, or to perform multitasking demands (e.g. merging into traffic and trying to maintain speed while driving (92%),<sup>65</sup> (listening and writing simultaneously,<sup>67</sup> or working according to tight schedules<sup>67</sup>). Adolescents with ASD used words like “*drowning*” for this overwhelming experience.<sup>59(p229)</sup> Providing information sequentially, for example as visual cues without time limits, allowing typing instead of handwriting, or teaching skills in small steps, ensures that information can be processed and thus provide both security and participation.<sup>18,64,65,67</sup> For the same reason, preparing adolescents mentally for new participation challenges supports participation. Additionally, adolescents with ASD know little about ways to access leisure activities.<sup>62</sup> After they leave high school, structured social activities of adolescents with ASD decline significantly.<sup>75</sup> Informing them beforehand, for example using video games or toy tractors as a basis for learning to drive, or visiting a new school before the transition is made, have also been described as supportive.<sup>64–67</sup> Since bullying is a frequent participation issue for adolescents with ASD, information about anti-bullying policies needs to be provided explicitly to these adolescents. This includes explanations of effective implementations, as an understanding of both contributes to their sense of security and supports participation.<sup>67</sup>

The second main theme, “**helping to connect**”, addresses how environments help to create and strengthen social relationships with others, and contribute to friendship and a sense of belonging among adolescents with ASD. Four different subthemes have been found to be central in helping them to connect.

The first subtheme, “familial environments”, refers to conditions provided by family, parents, siblings, grandparents, wider family members, or family friends. Besides siblings, these are mostly adult social partners who support the aim of social participation and activities in the community. Shared family activities like watching TV, attending church services, or performing leisure activities, have been described as supportive for participation.<sup>22,73,76,78,79</sup> Specifically, community participation like going

shopping or engaging in sports seems directly linked to a sharing familial environment.<sup>59,60,73,76</sup> This might be the reason, since in a large sample, the community participation rate did not drop after leaving school.<sup>57</sup> The same effect has been reported for unstructured social participation after leaving high school.<sup>75</sup> Others have reported how the company of a familiar person supports attending physical activities.<sup>71</sup> Additionally, a higher participation rate in leisure activities was found when the family climate was more sociable.<sup>22</sup> An important environmental condition for performing activities together is interests shared by family members,<sup>61,74,76</sup> whereas situations where siblings have different interests have been described as hindering participation.<sup>61</sup> Overall, the relationship between adolescents with ASD and their siblings seems to be of a similar nature as those in typical sibling relationships, involving overall enjoyment, responsibility, and reciprocity.<sup>61</sup> Hence, siblings remind adolescents with ASD of being similar and different. This is described to play a role in their process of identity formation.<sup>61</sup> Some adolescents with ASD perceive the inequality with their siblings as alienation from their family.<sup>61</sup> The role of a sibling may involve providing a bridging function to the experiences that adolescents with ASD encounter in social roles outside the familial environment. Family members often channel opportunities for social participation<sup>22,55,56</sup> or initiate activities.<sup>22,60,62,80</sup> Participation is hindered when organizational, emotional, or financial limits restrict families in providing these opportunities.<sup>60,62,79,80</sup> An example of this is when a family does not go to the cinema with an adolescent with ASD because family members cannot handle other people's embarrassment.<sup>60</sup> A higher family income also helps to connect with others,<sup>56,57,65,73,76,78,79</sup> as it provides opportunities and flexibility, and makes it easier to offer more options for participation, for example in physical activities,<sup>80</sup> or to pay for a case manager.<sup>57</sup> Restricted financial resources might reduce the social participation of families as a whole and consequently that of the adolescents as well. The higher the family income, the greater the frequency of invitations to activities.<sup>78</sup> The educational level of the mother also seems to influence participation,<sup>73</sup> as educated mothers might know better how participation can be achieved against the odds. There is a tendency for advocating families to be associated with more positive outcomes.<sup>55,56,67,79</sup> When families fail to facilitate social connectedness or to advocate for adolescents with ASD, this seems to hinder participation.<sup>55,59,60,67,72,80</sup>

The second subtheme, "friendships with peers and classmates", refers to environments provided by classmates at school or peers in the community, which are social partners belonging to similar age groups. For adolescents with ASD, friendships that overcome

disability and barriers are the overall goal of participation.<sup>56</sup> If their eagerness fails to elicit responses by peers, participation is hindered.<sup>63,81</sup> A “friend” was described by adolescents with ASD as “someone you can relate to” and “someone you can talk to”, and some of the defining characteristics were trustworthiness, patience, helpfulness, and kindness.<sup>19(p78)</sup> Friendship is experienced in conjunction with shared interests, shared activities, joy, and enrichment.<sup>19,55,56,74,76,78</sup> Shared interests and shared activities support participation.<sup>18,62,74,82</sup> Adolescents with ASD get to know friends in different situations: at school (51%), in the neighborhood (11%), in sports and leisure activities (9%), from childhood (15%), and through friends of the family (10%).<sup>76</sup> Over a third of the sample reported spending time with friends engaging in physical activities (37%), watching TV(25%), playing(25%), or conversing (23%). Adolescents with ASD were less likely to do outdoor activities (12%), or “hang out” with friends (8%), engage in artistic activities (4%), or listen to music(4%).<sup>76</sup> The use of social media also relates to connectedness.<sup>79,82</sup> It prepares for and at the same time reflects social relationships. Twenty-four percent of a sample played video games with peers.<sup>82</sup> From an environmental perspective, it is supporting when peers acknowledge that friendships with adolescents with ASD come about in a different way, and are therefore motivated to adapt.<sup>55,56,66,74</sup> This requires voluntary and reciprocal initiation.<sup>55,56</sup> Respect, often expressed by adolescents with ASD as a wish to be intellectually recognized,<sup>56,74,77</sup> seems a good indicator of a supporting environment created by peers or classmates. Participation can be described as successful when friendship with adolescents with ASD is mutually enriching.<sup>18,55,56,74</sup> In these cases, peers and classmates give the adolescents with ASD an insider role and ask about their wishes or preferences. Being allowed to select a partner supports participation in physical education.<sup>71</sup> Developing and systematizing a different communication style supports connectedness.<sup>55</sup> It reveals the importance of humor and allows the adolescents to discover their talents.<sup>55,74</sup> In contrast, even when being included organizationally, adolescents with ASD were described as being isolated or peripheral in classrooms for 71% of the time, and not protected by peers.<sup>19,70,81</sup> This indicates that successful friendship is a support mechanism against bullying.<sup>62,67,83</sup>

The third subtheme, “service and staff”, comprises the availability and characteristics of services, and how the staff providing these services influence social connectedness. Overall, receiving a greater number of community services<sup>73,79</sup> or and being educated in a fully or partially inclusive school environment<sup>22</sup> is associated with greater participation in social and recreational activities. But inclusion is not enough, since

being equal to other students is important. Thus, authority figures in the school setting must use consistent principles of equity, or equivalence with other students.<sup>56</sup> Administrative flexibility and pedagogic skillfulness influence the way support staff create equity and structure environments to connect adolescents with ASD with their classmates.<sup>74,79</sup> Unprepared, uninformed, and insufficiently skillful support staff hinders.<sup>55,63,67,68,77,80</sup> Such staff members might not be able to deal with challenging behavior, and might even constitute “a negative peer model”.<sup>55</sup> It is not easy to achieve just the right level of support. On the one hand, “over-inclusion”, or a constant level of support, can prevent or block opportunities for interactions with peers.<sup>56</sup> On the other hand, excluding the adolescents, for example due to disruptive relationships with teachers, obviously hinders participation.<sup>77</sup> Overt staff attention can be perceived as negative, as it accentuates the differences.<sup>68</sup> Skilled support staff provide relatedness and immediate reassurance, and serve as role model.<sup>55,68,77</sup> Skilled support should be provided subtly and in the background<sup>55,67,68</sup> to reduce the attention that adolescents with ASD get.<sup>74</sup> Resources to train support staff to work with adolescents with ASD are essential.<sup>56,66,68,72</sup> Lack of collaboration or dysfunctional collaboration between different staff members or between staff and parents has been reported as a hindering factor not only in school settings, but also for optimal care in hospitals.<sup>67,68,72</sup> As regards out-of-school services, only one-third of adolescents with ASD have been reported to participate in inclusive community group activities.<sup>78</sup> A lack of knowledgeable and flexible staff is also reported as a hindering factor when attending physical activities<sup>71,80</sup> or visiting hospitals.<sup>72</sup> Generally, more support and services in the community are required.<sup>57</sup> Others have reported the same for transition to work.<sup>66</sup>

The fourth subtheme, “reception of outing and attitudes of environments”, refers to the way disclosure of ASD is handled by the environment, and how attitudes of others influence relationships and thus participation. Many adolescents with ASD express the fear that disclosure of their autism may lead to negative reactions, or even result in stigmatization.<sup>60,68,77</sup> It hinders social participation when a disability is perceived as a weakness and not just as a different form of normality.<sup>55</sup> Adolescents who disclosed their medical diagnosis felt a constant obligation to control other people’s impressions and to show, for example, how “smart” they were.<sup>77</sup> In the context of work, participation is hindered when the presence of ASD implies doing a job less effectively than others.<sup>66</sup> By contrast, sensitively handled disclosure can facilitate understanding, empathy, and positive relationships.<sup>60,72,83</sup> A precondition for positive reception is an attitude that resists labeling and entrenched opinions.<sup>55</sup> Accepting differences implies a

negotiation of normalcy. When differences become normal and individualized, which was expressed in one article as “normal for me”<sup>66(p569)</sup>, this results in a fair chance of equality and support for participation.

## TENSION IN PARTICIPATION

During the thematic analysis, we discovered ambiguities regarding participation that influenced our attempts to define supportive or hindering environments. In order to still include them in our overview, we distinguished a third main theme, **“tension in participation”**. This refers to dilemmas regarding the participation of adolescents with ASD and is described with three subthemes.

The first subtheme, “isolation and solitary participation”, defined here as being deprived of participation with others, is described by words like “loneliness”, “exclusion” and “bullying”.<sup>63,81,83</sup> On the one hand, adolescents with ASD are socially more isolated.<sup>19,61,68,81,83</sup> Compared to other groups of pupils enrolled in special education, adolescents with ASD are significantly more likely to never see friends (43%), never receive calls from friends (54%), or never be invited to activities (50%).<sup>78</sup> In another sample,<sup>79</sup> 55% had not met up with a friend during the last 12 months. This has also been confirmed by others.<sup>57,75</sup> On the other hand, this should not be confused with the tendency to prefer solitary activities. Frequently reported activities<sup>22</sup> like walking (74%) and engaging in hobbies (41%) can be performed alone. It has also been reported that adolescents with ASD deliberately opt for solitude for reasons of restoration, regeneration, or concentration, which could be regarded as a form of participation for them.<sup>22,83</sup>

The second subtheme, “participation in disability-related groups”, refers to friendships and joint activities with other youths with disability. These seem to be frequent among adolescents with ASD. Over half of a sample were reported to have at least one friend with a disability<sup>76</sup> and the probability of belonging to a disability-specific group has been reported as being 25% more likely than among other adolescents.<sup>78</sup> On the one hand, this form of participation provides sameness and identity. Adolescents with ASD provide each other with similar levels of closeness, security, and conflicts, as typically developing classmates.<sup>19</sup> On the other hand, a low community participation rate has been found for adolescents with ASD who participate in disability-related social groups.<sup>78</sup> In any case, there is a tension regarding the function of disability-related groups. They may contribute to the participation of adolescents with ASD, and at the same time hinder their participation in normative groups.



The third subtheme, “normalcy and differences”, refers to the balancing act between “being different” and the need to “fit in”. On the one hand, difference separates, and adolescents with ASD feel a constant negative pressure to conform.<sup>68,77</sup> Ignoring this has negative connotations.<sup>68,74,77</sup> They often try to hide their differences, which in some studies is called “masquerading”.<sup>68,77</sup> This additional effort is described as frustrating and tiresome. Existing norms and enacted attitudes about ways of handling diversity influence the adolescent’s capacity for participation. On the other hand, when “*diversity becomes the norm*”,<sup>68(p40)</sup> pupils have been reported to feel more able to face the challenges and embrace the opportunities of the mainstream school environment.<sup>56,74</sup> Participation is achieved when there is a sense of normalcy, and the diagnosis of ASD ceases to be a person’s main attribute.

## VALIDATION BY STAKEHOLDERS

All seven stakeholders we approached for validation in our study considered their own experiences to be generally reflected by the findings presented to them. Most found the main themes and titles to be a helpful summary of the key environments which impact on adolescents with ASD. However, all commented on aspects which they felt should have been emphasized more, or which they felt were missing. For the sake of clarity, these topics are shown and commented on in Table 2.5.

**Table 2.5** Summary of validation issues mentioned by seven stakeholders.

Who	Topic (E = emphasis, D = disagreement, C = clarification, M = missing)	Addressed in the Review
Three adolescents and young adults with ASD	<ul style="list-style-type: none"> <li>- Individual differences (C)</li> <li>- Relationship to siblings is not reciprocal (D)</li> <li>- Social skill interventions (M)</li> <li>- Difference between team sports and individual sports (C)</li> <li>- Bright light and background noise are troublesome (E)</li> <li>- It is hard to know when somebody is losing interest. (C)</li> </ul>	<ul style="list-style-type: none"> <li>- this is true for all results</li> <li>- “familial environment”?</li> <li>- not mentioned</li> <li>- “social non-participation”, insufficient “staff and services”</li> <li>- “physical environment”</li> <li>- could be part of “informational environment”</li> </ul>
Two parents of adolescents with ASD	<ul style="list-style-type: none"> <li>- Importance of spiritual communities (E)</li> <li>- Meaningful employment (M)</li> <li>- More support for all stakeholders (E)</li> <li>- More awareness by society is needed (E)</li> <li>- Support by marriage partner (M)</li> <li>- The section “Tension of participation” is excellent (E)</li> <li>- Protection from negative social environments is insufficiently covered by “security” (C)</li> <li>- Environments are inter-related (E)</li> <li>- “equality but differentness” of ASD (E)</li> <li>- Phrases like “burden to society”, “disability” and “weaknesses” are disrespectful (D)</li> <li>- ASD is to be viewed as an ability and not as a disability (C)</li> <li>- On-going mentorship or “trusted adviser” for work (M)</li> </ul>	<ul style="list-style-type: none"> <li>- “reception of outing and attitudes”</li> <li>- yes, only two studies included</li> <li>- see discussion</li> <li>- “reception of outing and attitudes” see discussion on support by parents</li> <li>- we agree</li> <li>- see discussion</li> <li>- we agree</li> <li>- see discussion</li> <li>- “normalcy and differences”</li> <li>- we agreed and removed the first two of these phrases</li> <li>- “outing and attitudes”</li> <li>- could be “staff and services”</li> </ul>
Two community health professionals: A special needs teacher and an occupational therapist	<ul style="list-style-type: none"> <li>- Work spaces are often too distracting</li> <li>- Courses for siblings are needed (E)</li> <li>- Individual sport is not emphasized at school (C)</li> <li>- Role of parents needs to be emphasized (E)</li> <li>- Disclosure is a daily struggle (E)</li> <li>- Anti-bullying strategies must be visible and noticeable (C)</li> <li>- Financial resources to train teachers and staff (E)</li> <li>- Apprenticeship and employment are underrepresented (M)</li> <li>- Relational security seems extremely important (E). If achieved, even body contact is possible (M)</li> <li>- Their views are often underrepresented (E)</li> </ul>	<ul style="list-style-type: none"> <li>- “physical environment”</li> <li>- see practical implications</li> <li>- could be “services”</li> <li>- see discussion and practical implications</li> <li>- “outing and attitudes”</li> <li>- “informational environment”</li> <li>- could be “staff and services”</li> <li>- we agree</li> <li>- see discussion, body contact not mentioned</li> <li>- see discussion</li> </ul>

## DISCUSSION

The aim of this scoping review was to map the existing literature about supporting and hindering environments for the participation of adolescents with ASD. Thus, it focuses on the inter-relatedness between environment and participation for this group of young people. To our knowledge, such a synthesis has not been made before.

The number of studies retrieved, published between 2001 and 2018, confirms the large volume of autism-specific research being conducted,<sup>2</sup> but the fact that 31% of all scanned abstracts did not meet our age criterion (75% aged between 12-21 years) shows the paucity of research focusing solely on adolescents.<sup>84</sup> This scoping review includes adolescents with ASD with and without co-occurring intellectual disabilities, and represents the full spectrum of support needs, from requiring very substantial support to requiring relatively little support. In line with what was reported by others,<sup>7,85</sup> the majority of the abstracts we scanned covered the ICF participation domain of learning and applying knowledge (d1) and the environmental domain of products and technology (e1). Due to our strict inclusion criteria, these domains are poorly represented in the 31 studies, as has been confirmed by Bölte.<sup>86</sup> The 31 included studies mainly addressed three ICF participation domains (d7-d9). The areas of participation among the adolescents with ASD in our study covered mostly real and desired friendships, relationships, leisure activities, and transition. These areas are in line with what was found in other research on autism among adolescents.<sup>15,87</sup> Typical adolescence topics like independence, discovery of public space, sexuality, partnerships, or detachment from parents, were not covered by the research we mapped.

The first main theme we distinguished, “providing security”, is known from disability studies, where quality aspects of participation are described as, *“a sense of security as providing a foundation to pursue challenges and take risks in their lives”*.<sup>37(p1450)</sup> The security function of parents has been widely confirmed,<sup>88–90</sup> and it is often reported how the physical environment can hinder the participation of adolescents with ASD,<sup>91,92</sup> whereas providing agency and control over the physical environment support it.<sup>93,94</sup> The third subtheme, that of “informational environments” is a novel one. Information affects the security perception of adolescents with ASD, as their ability to derive information from social contexts is reduced.<sup>95</sup> An information-sensitive environment can contribute to their sense of security by providing different and more adapted

information. According to the “reasonable person model”<sup>30,31</sup> people can respond more appropriately when their environments support their needs for meaningful, focused, and comprehensive information.<sup>39,40</sup> This allows cognitive mapping, processing of information, and decision making, thus providing a sense of agency and control. This is suitable for adolescents with ASD, who require structure and predictability.<sup>96,97</sup> Used widely in the contexts of urban planning,<sup>98,99</sup> this model is also used in fields like fatigue and violence reduction.<sup>100</sup> It might support interventions to improve the participation of adolescents with ASD like orientation and way-finding, building confidence and trust in relationships, or creating restorative places in schools and community settings. Projects regarding architecture and design<sup>101</sup> and community services<sup>102</sup> offer encouraging examples in this respect.

The second main theme, “helping to connect”, mirrors the insider perspective reported in a disability study, in which participation is described as “*a means to experience social connectedness with others and communities*”.<sup>37(p1459)</sup> Adolescents with ASD often require improvement of their social interaction skills and are perceived as being less interested in social participation.<sup>84,103,104</sup> However, our findings show that adolescents want to be connected and to experience relationships, intimacy, and a sense of belonging. For adolescents with ASD, the “*familial environment*” for participation is just as important as it is for younger children with ASD.<sup>105,106</sup> Compared to typical adolescents, this is not age-appropriate. Wider families need to be supported in their efforts to connect adolescents socially, for example in visiting public spaces, or work internships. This seems a constructive way to meet the needs of caregivers for persons with ASD.<sup>107</sup> Special attention should also be given to siblings, as they can fulfil a bridging function.<sup>108</sup> Courses for siblings of adolescents with ASD can enable them to become allies in social settings, while at the same time they can reflect on and provide feedback on their sibling’s behavior in a way that adolescents are used to and can understand.<sup>109</sup> The reasonable person model can clearly be applied here as well.<sup>39,40</sup> It is the responsibility of the social and attitudinal environment to provide conditions and services to ensure that disclosure of ASD leads to connectedness and acceptance instead of separation.

Acceptance is also addressed in the third main theme, “tension in participation”. The above-mentioned disability study expresses that “*very different patterns of participation can still reflect full participation*”.<sup>37(p1459)</sup> Although our results address

different pattern of participations, including solitary activities<sup>25,110</sup> and participation in disability-related groups, “isolation and solitary participation” is the most striking aspect, as it seems to contradict the term non-participation as used by Hart.<sup>36</sup> Non-participation according to Hart covers the three lowest steps of the participation ladder: “*manipulation*”, “*decoration*”, and “*tokenism*”. Participation, as described here, rarely goes beyond Hart’s “*tokenism*”.<sup>36</sup> Although the adolescents with ASD are apparently given a voice, in fact they have little or no choice in the subject or style of communication, and little or no opportunity to make their own decisions. Results of our study show that it is the role of friend that adolescents with ASD long for. This is appropriate for their age, is strongly expressed, and is similar to what is experienced by other youths with disability.<sup>111</sup> From the perspective of Hart’s theory<sup>36</sup> it might be questioned whether the importance of friendship for adolescents with ASD is sufficiently acknowledged in current service provision and in autism-related research. Similar to what has been found for other disabilities,<sup>112</sup> participation in disability-related social groups and friendships between adolescents with ASD allow them to form a positive identity, and to escape the constant pressure to fit in. Recent work suggests that “camouflaging” ASD, or as it is called here “masquerading”, often requires substantial efforts, may lead to stress responses and may have a negative impact on the development of identity.<sup>113,114</sup> This is important for participation, as the normative values that constitute “participation” have not yet been defined or agreed on.

## LIMITATIONS AND STRENGTHS

There are some limitations associated with this review. Due to the overwhelming number of articles, we found initially, we did not search any further in the grey literature and performed no new database search in 2018. Relevant data may thereby have been missed. We performed a hand search of the reference lists of the included articles and hand-searched 4 autism-related journals from 2015 – 2018 to provide current data. There is also the risk of selection bias. Overlaps between the definitions of ICF categories could hardly be solved. Specifically, social relationships (classified in ICF both under participation (d7) and environment (e3)) were impossible to differentiate clearly, as they reciprocally influence each other. As has been proposed by others,<sup>28,37</sup> the additional focus on social and occupational roles brought some light into this. Identifying roles makes the demands regarding environments, for example in the role of sibling, more explicit. Our focus on ecological validity led to the exclusion of environmentally based intervention studies. Although most interventions directly or

indirectly influence the environment of the adolescent with ASD, studies mostly fail to assess their effect on participation in natural contexts<sup>115</sup> and thus provide no answer to our research question. Methodological strengths lay in the consistent use of the perspectives of adolescents, parents, and peers regarding participation. In addition, the interdisciplinary nature of the research team widened the scope. Furthermore, involving stakeholders to validate the findings and achieve a stakeholder-sensitive, yet scientific presentation is a step rarely reported in scoping studies<sup>49</sup>.

## CLINICAL IMPLICATIONS AND FURTHER RESEARCH

Practitioners might consider the results of our research for their practice by looking at the environment as a powerful tool to support the participation of adolescents with ASD. As participation is subjective and value-loaded, the adolescents themselves should identify environmental aspects hindering and supporting their participation. The main themes of “security”, “connection” and “tension” can serve as guiding concepts to address possible fields of change. Overall, professionals need to support parents, siblings, peers and staff dealing with adolescents with ASD. Providing relational security enables adolescents with ASD to become risk takers in activities and participation. Professionals need to be careful to prevent further stigmatization. ‘They should address the aspects that make adolescents with ASD different from typically developing adolescents’ without labeling them. Service providers ought rather to focus on staff training, implementation of anti-bullying policy and reviewing the way they provide information to adolescents with ASD.

Further research should focus on acquiring insights into the perceptions and informational requirements of adolescents with ASD regarding participation, in natural contexts, specifically with respect to friendships, out-of-home and out-of-school participation, and work. We further need to research the parents’ strategies and experienced outcomes as regards encouraging participation by influencing environments. The use of the “reasonable person model” for this potentially offers a new way to examine the interaction between participation and the environment in everyday contexts.

## CONCLUSIONS

This scoping review shows that there is a complex interrelation between the participation of adolescents with ASD and their environment. Security and connection are the most important environmental aspects regarding the participation of adolescents with ASD and their strong desire for positive peer relationship experiences. Security and connection represent meaningful, subjectively relevant, and feasible aspects of the way in which the environment can shape participation.

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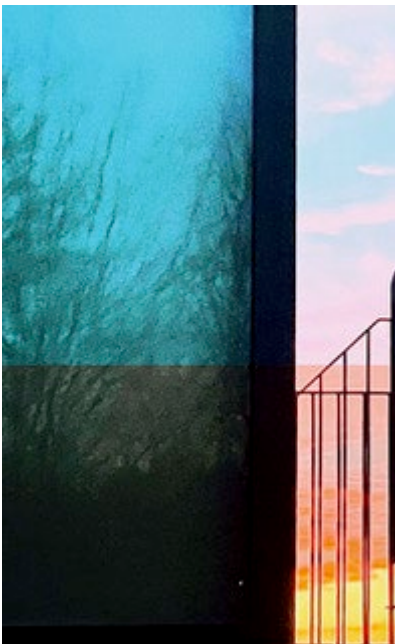
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# CHAPTER 3

Environmental pre-requisites and social interchange:  
the participation experience of adolescents with  
autism spectrum disorder in Zurich



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*Disabil Rehabil* 2021;43(26):3789-802

## ABSTRACT

### **Aim**

Participation of adolescents with autism spectrum disorder hardly occurs in settings outside of home and school. Little is known about how their participation is influenced by environmental factors. This study explored how and why adolescents with autism spectrum disorder perceive aspects of their environment as facilitators or barriers to their participation outside of home and school.

### **Method**

This explanatory case study explored the participation experiences of adolescents with autism spectrum disorder (15-21 years) from Zurich and surroundings with in-depth interviews and photo-elicitation, using photos made by the participants during activities outside of home and school. Data was analyzed with a 7-step procedure.

### **Result**

The presence of two main themes seemed necessary to facilitate participation outside of home and school: 'environmental prerequisites to attend activities', which consists of five subthemes, such as 'the company of trusted persons' and 'the provision of knowledge and information', and 'social interchange and engagement', which consists of three subthemes and describes how actual involvement can be supported.

### **Conclusion**

Our findings highlight the influence of trusted persons on adolescents with autism spectrum disorder, and the need to extend the support network for these adolescents to other individuals, services, and society so that their participation in activities can be encouraged.



## INTRODUCTION

Participation of adolescents with autism spectrum disorder (ASD) hardly occurs in settings out of home and school, which includes public areas, leisure places or places of friends and extended family.<sup>1,2</sup> This means that these individuals are not exposed to a wide range of age appropriate activities that their non-ASD counterparts do experience such as sports, mobility, attending cultural events, shopping, working or socialising with friends.<sup>3,4</sup> Participation, defined by the World Health Organization as *“involvement in life situations”*<sup>5(p10)</sup> is extended here to *“being engaged in and /or performing meaningful activities in occupational and social roles while attending.”*<sup>6(p2)</sup> Participation is generally seen as requiring both attendance, understood as “being there”, and involvement, which includes elements of engagement, motivation, persistence, social connection and levels of affect, within the environment.<sup>7,8</sup> For adolescents with ASD, participation is an entry point for learning and social development, as it is interwoven with family, peers, public life, and society, all of which are parts of their environment.

Many different definitions of environment are used in the literature. In this paper ‘environment’ is regarded along the lines of the definition provided by the World Health Organization, which defines the concept as *“the physical, social, and attitudinal environment in which people live and conduct their lives”*.<sup>5(p5)</sup> Environment, in this definition, has been identified as being an important influential factor on participation, particularly for youth with disabilities.<sup>9–12</sup> Environments act as mediators and they can serve dynamically as either barriers or facilitators for participation of adolescents with ASD.<sup>6</sup> It has been established in the field of environmental psychology that, to be optimal for the facilitation of participation, environments firstly need to provide information, such as descriptions of social rules and processes, provide secondly meaningful choices to participate actively, and last facilitate interactions that pursue a restorative character.<sup>13,14</sup>

Scientific studies that focused on a combination of autism, environment and participation have, so far, delivered (mainly) fragmented knowledge.<sup>15,16</sup> More precisely, existing research has largely focused on particular age groups and settings: adolescents are less researched than children<sup>6</sup> and the majority of studies look at home settings<sup>17–19</sup> and school settings.<sup>20,21</sup> It is clear, then, that the adolescent age group should be given (more) attention. All the more, as, for most adolescents, settings out of home and school are essential to socialize and transit to adulthood.<sup>22</sup> Although adolescents with ASD value friendships and joint activities with youths<sup>1</sup>, their reported

communal participation rate is low.<sup>23</sup> Additionally, the reported environmental supportiveness for community participation of adolescents with ASD is low as well.<sup>3</sup> Adolescents with ASD might avoid participation experiences because they feel pressured as a result of their efforts to balance the idea of “being different” with the need to “fit in”.<sup>24</sup> Constant pressure is tiresome and contradicts involvement. Research reports a decrease in the development of functioning after leaving high school in adolescents with ASD.<sup>25</sup> This decrease might be a consequence of missing age-appropriate participation experiences.<sup>26,27</sup> The lack of these appropriate experiences might also have negative consequences on independence in work and adulthood.<sup>28,29</sup> In addition, a lack of age-appropriate participation experience can affect health and quality of life in a negative way.<sup>27,30–33</sup>

There is growing demand that autism research should incorporate the experiences and values of individuals with ASD themselves.<sup>34,35</sup> At the moment, however, there is, to our knowledge, still only limited literature on the way in which adolescents experience environmental factors, and the way in which these adolescents think these factors influence their participation (this has only been studied in home and school settings).<sup>4,18,21</sup>

In an attempt to fill this knowledge gap, the objective of this study was to gain in-depth insight as to how and why adolescents with ASD perceive aspects of their environment as facilitators or barriers to their attendance and involvement in activities outside of home and school? Given that the interplay between environment and participation is dynamic, we were particularly interested in grasping the turning point when an environmental facilitator becomes a barrier and vice versa, which we described as ‘tension’. Only if we know how the environment affects people with ASD, and how it gives shape to facilitators, barriers, and tensions, can we try to support participation of adolescents with ASD by creating strategies to adjust and optimize their environments.

## MATERIALS AND METHOD

In order to answer our research question, we conducted a qualitative, case study, while closely adhering to the methodology set out by Yin.<sup>36</sup> More specifically, we focused on the experiences of adolescents with ASD in a particular geographical area.

## THE CASE: THE CANTON OF ZÜRICH

The canton of Zürich was selected as case, for two main reasons. First, hardly any research has been conducted in the canton of Zürich regarding environment and participation of people with ASD. Secondly, the situation in the canton of Zürich means that there are likely little to no other (non-ASD related) reasons for a lack of participation. The canton provides a relatively stable, secure, and well-defined environment for all who reside there. It provides a high quality of life, as well as an economically prosperous, and multi-cultural setting.<sup>37,38</sup> The social health system covers almost all costs of children's education and therapy. Most adolescents with ASD in the canton of Zürich attend public school and live at home.<sup>39</sup> Public transport functions well in this canton and it aims for equal accessibility for all. We found, however, that, although the canton of Zürich has been working on the implementation of the United Nation convention on the rights of persons with disabilities (ratified by Switzerland in 2014), and has made progress in doing so, the extent of facilities and support for persons with cognitive or social difficulties, like ASD, is still rather limited. A noise reduction area and/or the use of simple language would be beneficial for them. Finally, looking at the manner in which the two local daily newspapers (Neue Zürcher Zeitung and Tagesanzeiger) dealt with autism between 2014 and 2017, which offers a glimpse into the way ASD is dealt with by the community in general, it is apparent that ASD is mainly either idealized (indicated by newspaper features about extraordinary people with ASD and successful work stories of people with ASD in informatics) or as something strange and in need of a solution (indicated by features about diagnostics of ASD and discussions about the causes of autism). There is only limited attention for the day-to-day reality of living with ASD, and the needs of people with ASD. This, more assertive approach, is only employed by one social media platform<sup>40</sup> and a client organization for autism (autismus deutsche schweiz<sup>41</sup>), which launches campaigns for autistic friendly environments in theatres, collaborations with hairdressers and dentists and quiet hours in shopping malls.

## PARTICIPANTS

Participants had to fulfil several criteria to be eligible for this study. We were looking for adolescents between 15 and 21 years of age, who were diagnosed with ASD (according to ICD-10 standards) by a physician, and who participated in at least one activity outside of home and school without being accompanied by someone. In addition, the adolescents had to have been living in the canton of Zürich for at least

3 years and had to be able to communicate verbally or with assistive devices in local languages. Adolescents were excluded if they attended sheltered housing or workplaces and/or if they were supervised 24 hours a day.

Three sampling techniques to find participants were used. Firstly, we conducted a purposive sampling by asking 42 key persons like teachers, physicians, therapists, and employers, to approach adolescents with ASD. Although some rejected aiding our study, as they feared it would cause adolescents with ASD too much distress, a total of 38 informants supported this stage of recruitment. Secondly, we conducted self-selection sampling by presenting the project in autism specific social media. Finally, we used snowball sampling and asked adolescents with ASD to attract peers with ASD. Six male and two female participants consented to participate, however, the two females resigned during the photo-collecting phase. The study obtained ethical approval from the Zurich Ethics Committee (25.4.2017 BASEC-Nr.2017-00262). Participants and parents received written and verbal information and provided informed consent. Participants gave consent for the publication of their photos. As a sign of gratitude, adolescents received a book voucher.

Data was collected by first using photo-elicitation and then conducting in-depth interviews. The method of photo-elicitation was used as it has been demonstrated to have specific benefits for collection data about deeply emotional experiences, and collecting data from less expressive participants and youth with ASD, as well as from people who have stigmatized conditions, such as mental illness<sup>42,43</sup> and adolescents with ASD.<sup>44</sup> First, photos were gathered: the participating adolescents were instructed to take photos of activities they participated in over a period of two weeks. They were asked to specifically focus on three participation experiences outside of home and school that they liked, disliked, and felt a certain tension or unease about. After this period, they selected (at most) 15 photos, coupled them with either a title or a brief written description, and passed them on to the researchers. Second, the experiences of these adolescents with ASD were assessed discussing their experiences using photo-elicitation during in-depth interviews. The interviews were conducted in accordance with an interview guide that had been prepared beforehand, and which had been improved based on feedback obtained from an adult with ASD. The main changes aimed at making the questions in the guide simpler and straightforward. The in-depth interviews started with general questions (e.g., "Please explain this photo") and

continued with more probing questions (e.g., “Why did you take this photo?”). Concepts of theoretical assumptions guided further questioning (e.g., “When do you feel you are engaging in participation?” and “Do you feel well-informed during your participation?”). Six participants, including the one from the pilot interview [P1], fulfilled all data collection steps (Table 3.1). Most participants were coached by their parents [P2,P3,P4,P5] or therapist [P1] during the photo collection process. Overall, data collection yielded 12.75 hours of interviews and 69 photos.

**Table 3.1** Characteristics of Participants

Participants		1	2	3	4	5	6
<b>Age</b>		16 (pilot)	17	15	16	20	20
<b>Gender</b>		male	male	male	male	male	male
<b>Diagnosis</b>	ASD	Asperger	Asperger	Asperger	Asperger	ASD	Asperger
	co-morbidity	none	ADHD	none	ADHD	social anxiety	migraine
	age at diagnosis	7	8	7	9	6	12
<b>Parents</b>	marital status	separated	married	married	married	widow	married
	education	low	middle	high	high	middle	middle
	mother education						
	father education	high	low	high	high	low	high
<b>Living Condition</b>	with whom	mother	parents	parents	parents	mother	alone*
	location	rural	urban	suburbs	suburbs	rural	urban
<b>School/Work</b>	type	private school	private school	regular school	internship	apprentice-ship (polygraph)	university (informatics)
	support	individual learning plan	individual learning plan	small class	special needs support	special needs support	non
<b>Interview place</b>		school garden	home	home	café	therapy place	university

\* weekends with parents

## DATA ANALYSIS

The interview data were transcribed verbatim. Data was analyzed in seven steps as described by Yin.<sup>36</sup> Each adolescent was seen as one “unit of analysis”.<sup>37(p3)</sup> First, the members of the research team acquainted themselves with the photos and descriptions of each unit of analysis to get a general sense of the data. Next, the research team reflected on how best to code the data without losing the meaning of the interview as a whole. We decided to use four preliminary broad categories (‘facilitator’, ‘barrier’, ‘tension’ and ‘explanation’) to describe (the explanation for) the effect of environments on participation. Technically, aspects of environments were defined as ‘*facilitators*’ when they provided conditions to feel secure, welcome, socially

accepted, experience fun, pleasure, or positive self-esteem during participation. Aspects of environments were defined as '*barriers*' when they provided conditions to intimidate, to provide physical or social distance or exclusion, stress, negative feelings like non-motivation or anxiety or incomprehensiveness resulting in non-participation. Aspects of environments were defined as '*tension*' when they provided conditions that generated ambivalent or contradictory feelings causing insecurity or unease during participation. Reasons behind an aspect of an environment being placed in one of the three beforementioned categories were categorized as '*explanations*'. The words of one of the participants with ASD [P5] can serve as an example of how the coding process worked in practice: an environmental condition that led this participant to refrain from using public bathrooms was their smell. We defined the smell of public bathrooms as a 'barrier'. The same adolescent explained that he imagined such a bathroom as being "dirty and insane". We coded "image of dirt and insanity" within the category 'explanation'. After defining the four central categories, we read and re-read the data and classified all data that was covered by them, leaving out any data that did not fit at least to one of the categories. This resulted in a total of 1199 coded quotes. Then, the first author and another researcher independently clustered the coded quotes of each participant (unit of analysis) into an individual pattern.<sup>36</sup> For each participant, the two patterns that were created by the two independent researchers were matched.<sup>36(p143)</sup> and the team assigned more abstract labels to them, covering the meanings of the coded quotes and at the same time taking care that these labels were analytically mutually exclusive. Subsequently, the complete research team discussed the results, while also keeping in mind the received photos, which expressed engagement and/or restraint from participation. Next, two of the researchers merged ("matched") the six individual patterns into one common pattern. The complete research team then discussed rival explanations as well as theoretical ideas and assumptions that might explain this common pattern and refined the results further. After coming to an agreement, the research team formulated the results with two main themes and 8 subthemes.

## TRUSTWORTHINESS

Following the recommendations of Guba & Lincoln<sup>45</sup> we used different strategies to guarantee/protect the trustworthiness of this study. Credibility was ensured through data triangulation, an iterative peer-debriefing, and a member-check procedure, for which 4 participants reviewed a short summary of their interview (two participants did

not respond to this request, even after two reminders). Transferability was guaranteed by providing a well-documented context and research process and displaying photos. A rigorous decision trail and researcher triangulation during analysis contributed to the confirmability and dependability of the study. Finally, for reflexivity, research diaries and research team meeting notes were stored.

## RESULTS

The analytical process aimed at answering the research question of how and why adolescents with ASD experience facilitators, barriers, and tension in their environments during attendance and involvement in activities outside of home and school, led to the identification of two main themes. The first main theme '*environmental pre-requisites to attend participation*' appears to be imperative to start participation. It consists of five subthemes: (1) the company of trusted persons, (2) the presence of a nudging drive; (3) the provision of knowledge and information, (4) the presence of good vibes, and (5) the design of the physical environment. The second main theme, '*social interchange and engagement*', consists of three subthemes: (1) being approached, (2) becoming a group member, and (3) being acknowledged and gently guided. In this section, general aspects about participation of adolescents with ASD in the canton of Zurich are described first, after which general insights into these main themes and subthemes are given together with exemplary comments and photos acquired from specific participants. Facilitators, barriers, and tensions are presented for each subtheme both in the written text as well as in the corresponding tables.

Participation of the six male adolescents with ASD in activities outside of home and school in the canton of Zurich turned out to take place in a variety of areas (Table 3.2), and to be performed regularly and consistently. The favorite activity among the participants was using public transport. Interestingly, all participants perceived participation as a social act. Although this is obvious for group activities such as volleyball, this finding requires explanation when it comes to solitary activities like attending libraries or hiking in an open, vast landscape. For a person with ASD, even the possibility of meeting somebody, during a seemingly less social activity, often feels like a social event and therefore often feels less easy. The following photo (Figure 3.1) and matching quote illustrate this seemingly counterintuitive feeling.

**Figure 3.1** Sunday walk", data retrieved on Sunday August 27<sup>th</sup>, 2017 13:28

«Nearly every Sunday I go for a walk with my mum. Mostly we walk around our village, but sometimes we drive to nice places. Weather does not matter. I love to be in nature and see changes. Always different with all kind of weather. Meanwhile, I know all the paths around our village. Yet, it is still stressful to know that people might come towards us and I have to greet them. Before, when I see them, I would have run away. Now, it is a bit easier, I can stand it, but still...». (Participant(P)5).

**Table 3.2** Areas of Participation (activities or situations).

Participants	1	2	3	4	5	6
“Like to participate”	Bus	Bus	Bus	Bus	Bus	Public dinner
	Train	Train	Train	Train	Train	Workplace
	Guitar lesson	Tram	Music class	Tram	Walking	Sports
	Shooting club	Reading in the park	Station	Fishing club	Hiking	Concert
	Riding in the car	Taekwondo	Cinema	Volleyball	Fitness club	Boat trip
	Restaurants		Walking the dog	Archery	Library	University
“Dislike to participate”				Visiting friend	Family visits	study room**
				Museum	Skiing	
	Funerals	Disco	Skiing	Disco	Workplace	
		Parties	Shooting club	Bar	Public bathroom	None
“Tension”		Bar	Art		Long-distance travelling	
		Public swimming pool				
	station*	Zoo	Youth club	Shopping	Receptions	Parties
	busses*	Museum	Church	Cinema	Shopping	University
		Cinema		Workplace		study room**

\* during rush hours    \*\*two different study rooms



## MAIN THEME I: ENVIRONMENTAL PRE-REQUISITES TO ATTEND ACTIVITIES

The first main theme comprises five environment-based subthemes that influence whether adolescents with ASD would attend and participate in an activity (Table 2.3). For these adolescents to attend and participate in new environments, facilitators from all five subthemes must be present, while the presence of any barrier would result in non-participation. Due to the dynamic nature of environments, each facilitator can reach a turning point, which we call *tension*, and as such convert into a barrier.

**Table 3.3** Main theme I: Environmental pre-requisites to attend activities.

Subthemes	Facilitators	Barriers	Tension
<i>Company of trusted persons</i>	Trusted persons with long-term relationships Persons initiate, prepare, organize, and accompany Persons provide enjoyment of being together	Missing familiar person Pursue different interests and refrain from shared joy	Trusted persons are less reliable or capable Inability to initiate or organize
<i>Presence of a nudging drive</i>	Aims and obligations are communicated Authentic learning activities Meets adolescent's interest and their active approval Activities involving regular, manageable motor skills	Aims or obligations are not provided Fail to address adolescent's interests Construction of artificial or difficult activities	Presence of competing volitional factors to participate
<i>Provision of knowledge and information</i>	Insight into organizational processes and rules Spatial orientation Structure, regularity, frequency, intensity grading of participation Security through feeling of preparedness	Underestimating preparation to get informed Inability to provide structure, regularity, or adaptation to the adolescent's learning process Underestimating needs for sameness and security	Unforeseeable situations with problems Participating too early without enough routine or preparation
<i>Presence of positive vibes</i>	Friendly, kind social climate Funny persons are less intimidating Lightness and ease	Moody, rough, impolite, or offensive social climate Openly sad situation Conflicting situation Stress	A lapse in a generally positive, friendly atmosphere.
<i>Design of the physical environment</i>	Possibilities of influencing physical features Availability of diverse spaces that are well labelled Prevention of density through architecture and regulations	Uncontrollable physical features No quiet places Unforeseen density	The sum of physical environmental aspects Fatigue and stress accelerate the perception of physical features negatively

The first subtheme, the company of trusted persons, describes enacted company from well-known and therefore trusted persons with whom adolescents have a long-term relationship, most often parents, grandparents, siblings, a close boyfriend [P4] or girlfriend [P6]. In a supportive environment, these trusted persons actively initiate, organize, and accompany participation of adolescents with ASD. Adolescents with ASD participate because they wish to be together with their trusted persons and enjoy shared well-being. Company is usually needed for extended periods, as expressed in the following quote (combined with Figure 3.2).

**Figure 3.2** “Together at the fishing club”, data retrieved on Wednesday December 6th, 2017, 20:39.



*«This was taken during the end of year meeting at the fishing club. My father was invited, and I accompanied him. I am now a member of the club for several years, but I always go to the meeting with my parents » [P4].*

All new activities that the adolescents with ASD participated in were experienced in the company of trusted persons. Their absence acted as a barrier to participation. Absence of trusted persons can occur as a result of them being constrained by time limits, having a lack of interest or experiencing boredom in shared activities. At times, even the company of trusted persons can be a cause of tension. This occurs, for example, when the mood of a sister turns negative during a social activity, or when parents fail to provide organizational support for their shared activity. One participant's dog [P4] provided comfort and company, but the dog's presence could not initiate the participation of his owner in new participation areas.

*Presence of a nudging drive* is the second subtheme that affects whether an adolescent with ASD would attend and participate in an activity. It comprises elements of obligation, habituation, interest, and motivation and addresses adolescents' volition for participation. Understanding obligations and/or the aims of an activity was as important for adolescents with ASD in supporting their participation as meeting their interests was. To facilitate this understanding, it is essential that other people within the environment clearly communicate these obligations and aims. For example, one participant mentioned in connection with his membership in the fishing club. He didn't like to clean the communal pond. But he was informed that it was obligatory for all members to clean it once a year. He also understood the aim of this activity: a clear pond for the fishes. This nudged him to participate in cleaning the pond (a not always pleasant experience). Authentic situations in general, such as job-shadowing, also encouraged participation [P3-P5]. If adolescents were interested in the activities and actively consented to engaging in them, participation also increased. Activities that involve the performance of regular, manageable motor skills, including walking a dog and exercising at a gym, also functioned as nudges to facilitate participation. It was experienced as a barrier to participation if obligations or aims were not communicated or interests were not met. Artificial activities, such as occur in roleplays, were also mentioned as being not supportive. Competing volitional factors, for example when an activity was uninteresting but obligatory, or when motivation was connected with one's energy level, generated tension in the motivation of adolescents with ASD to participate in activities (see Figure 3.3).

**Figure 3.3** "Dinner as thanks for helping at a caritative event", data retrieved on Thursday October 17th, 2017, 18:26.



*«It is a tension. On one hand, it is nice to get an invitation and to be together with people that I already know a bit. On the other hand, it is exhausting to go home late..... I have to learn to use less energy to hang out with others. My girlfriend has helped me a lot to this end. But yes, it is exhausting » [P6].*

*Provision of knowledge and information*, the third subtheme, expresses the need of adolescents with ASD for insight and understanding into the structural and social framework of the activities they might be participating in, as well as acquaintance with organizational processes and rules, such as those associated with using the tram (explained in the quotation below). It also includes spacial orientation regarding any (social) activity prior to attending. One adolescent explained why he likes using the trams (see Figure 3.4 in the inner city of Zurich).

**Figure 3.4** “The tram in Zurich”, data retrieved on Friday July 7th, 2017, 13:10.



*«In the inner city I prefer to use the trams. They use tracks ...so everything is given to the drivers...so they travel mostly the same routes. Thus, I do not have to rack my brain as to where I am...as with busses. Everything is given and much easier. You only have to watch the timescale. It is easy. You just must follow the colored lines; each tram has a different number and color. The 3 and 11 is green, the 13 yellow, the 2 red. The 4 is blue... you see - easy to understand. I know them all. » [P2]*

Structural aspects, such as regularity, frequency and grading of intensity were supportive to the participation of adolescents with ASD in activities, because the

feeling of being knowledgeable provided them with a sense of security and relaxation. One participant summarized his activity of serving at the fish market explaining that he loves to participate when he is knowledgeable:

*«I like doing when I know how to do it. At the annual fish market, we serve always the same: fish and chips, all kind of beverages, I know them all.... I like this. I serve once a year at one day...serving fish and chips and beverages and money and all this... and I can keep the tips. » [P4].*

Adolescents with ASD perceived it as a barrier if others underestimated their need for (extensive) preparation to get informed about and get acquainted with the norms and rules that exist in the activity in question. Considering their desire for knowledge and information, adolescents with ASD often refused attending unfamiliar activities, as they missed the sameness and security. In addition, facilitators became situational tensions when adolescents faced unexpected problems. One adolescent explained that attending receptions was a situational tension for him, as he would meet unknown persons, he hadn't had a chance to prepare to meet. Participation in activities during which there was insufficient time to prepare on the spot for new unforeseeable interactions, or to reflect on the circumstances and changes at hand also generated tensions in connection with provision of knowledge and information.

*Presence of positive vibes* is the fourth of the environmental prerequisites for adolescents with ASD. It describes a generally helpful climate that facilitates participation. One adolescent explained why he liked attending the shooting club (see Figure 3.5).

**Figure 3.5** “In the shooting club”, data retrieved on Tuesday July 18th, 2017, 13:24.



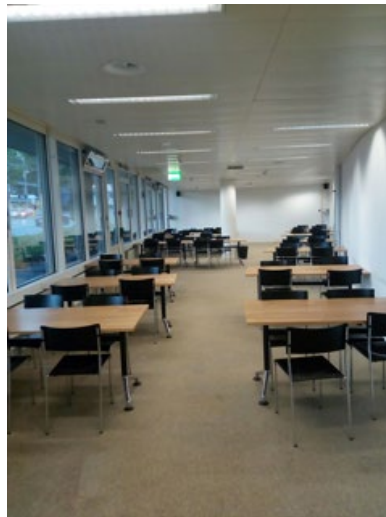
*«What affects me is the attitude of people. ...for example, in a club... if somehow the people are always in a bad mood, then my interest for it fades away and I feel like I am out of place. For example, in the shooting club, I feel fine. The atmosphere is friendly and nice. They talk in a friendly way, and you see how well they treat each other...well I can't explain this more in detail; it is not easy. But I like to be there» [P1].*

Friendliness, facilitated through a certain lightness, promoted the participation of adolescents with ASD. In such an atmosphere, they felt there were fewer expectations on them, and they experienced less stress. The latter was also experienced in funny situations. Rough, impolite, and offending social atmospheres intimidated adolescents with ASD and acted as barriers. Likewise, adolescents felt incompetent in reacting appropriately to sad or conflict-laden situations. Tension occurred when there was a lapse in a generally positive atmosphere, such as when a moody person was present and expressed negative vibes.

*The design of the physical environment*, the last of the five subthemes of the first main theme that need to be fulfilled for adolescents with ASD to attend and participate in an activity, addresses the effects of physical features of settings, including noise, light, touch, smell, temperature, and vibration. The sense of space and density experienced by the adolescents with ASD also falls under this factor. Sensory features affected all participants, but individuals' experiences with them were different, nonetheless.

Sensitivity to physical features that were present at activities was dynamic and could be influenced by an adolescent's level of fatigue, habituation, and personal maturation. Having agency over the sensory input they experienced supported the participation of adolescents with ASD. Sound and noise were most often described by adolescents as features that affected their concentration negatively and caused restlessness. Physical features could hinder participation of adolescents even when they felt passively exposed to them. An example of this given by one of the participants in this study was the vibrations of a nearby highway that affected sleep and provoked headaches [P6]. These vibrations reduced the number of sleepovers at his girlfriend's home, which resulted in him spending less time with her. All participants described having enough space as being a pleasant and important feature for their participation, and they often evaluated rooms in terms of the sense of space they offered, as shown in Figure 2.6. Well-labelled spaces, such as libraries or shooting clubs, were preferred as they allow overview and orientation.

**Figure 3.6** "University student study room", data retrieved on Thursday October 19th, 2017, 18:26.



*«This is one of my preferred study places at the university. It is spacious. Talking is allowed. Mostly I am there at 8 in the morning and I can choose a place to sit. Few persons, 2 or 3 of them, are there at that time. This is pleasant, as it is quiet. If possible, I would sit in the same place, as there is an electrical outlet and I can oversee the entrance ».* [P6]

Adolescents with ASD felt that crowds strongly minimized their personal space. Crowds also affected their agency by limiting their free movement. Some adolescents considered crowds as barriers as crowds increase the chances of being touched unpredictably. For one participant, the anonymity in cities was relaxing [P6]. Although physical context mattered in terms of attendance of and participation in activities, we found that the extent of differences in the individual experiences with physical context did not allow specific features to be clearly distinguished as facilitators or barriers.

Overall, all five environmental prerequisites (subthemes) had to be present for participants of this study for them to attend new activities. Once attendance is secured, the presence of some of the prerequisites, such as the company of trusted persons, was less necessary for participation and they could attend alone. All participants indicated that they were able to use public transport on their own, after initially requiring company. Only five other activities were performed without company, namely attending a gym [P5], sports groups [P1,P2,P6], individual music lessons [P1,P3], vocational-related lectures [P4,P5,P6], and visiting a museum [P4].

## MAIN THEME II: SOCIAL INTERCHANGE AND ENGAGEMENT

The second aspect that is crucial for participation of adolescents with ASD, and which provides insight into the question of how and why adolescents with ASD experience facilitators, barriers, and tension in their environments while they are attending and participating in activities outside of home and school, concerns social interchange and engagement. This aspect is related to the occurrence of social reciprocity when adolescents with ASD interact with persons other than their trusted persons during social activities. Such encounters include meeting persons occasionally (e.g., street, library, bathrooms), meeting acquaintances of others (e.g., concerts, university, receptions), passing break times with colleagues, and attending group events (e.g., university, work, leisure). Since adolescents with ASD were often uncomfortable about these situations, they were less likely to take photos. However, they explained the situations extensively in the interviews. Engagement in such social situations is a balancing act, which is reflected in the fact that this type of social interaction was the cause of most of the ‘tensions’ that were indicated by participants. Three subthemes were identified within the second main theme (Table 3.4).



**Table 3.4** Main theme II: Social interchange and engagement.

Subtheme	Facilitators	Barriers	Tensions
<i>Being approached</i>	Proactive behavior Being asked Patience for answers	Lack of pro-active approach Lack of invitation Lack of explanation	Overstraining approaches Gazing problems
<i>Becoming a group member</i>	Organized group session Clear rules for communication Less priority of talking	Large, informal groups Irregular meetings Quick conversations	Pace (velocity) Feeling inhibited in reacting
<i>Being acknowledged and gently guided</i>	Provide positive feedback Indicating gently what to do Acceptance Expression of gratitude for presence	Negative feedback Low tolerance Stigmatized judgement	Small issues can set off feelings of inappropriateness

*Being approached*, the first subtheme, focusses on how communication, and specifically talking with each other, starts. Adolescents with ASD described how they wished to be talked to by others. The university student [P7] comments on this:

*«It is more likely that I stand alone than somebody approaches me. I am one out of ten in a mass of 1000 persons who stands alone. It feels like being fool....It would be easier for me if they approached me»* [P7].

All participants described it as facilitating, when verbal interaction was initiated by others, particularly with small comments or short questions. And, as the adolescents required time to reflect on how to respond correctly, the people who engaged with them had to be patient. During initial social interactions, adolescents required additional time to focus on the question of how and where to gaze. Finding the right balance between gazing at and looking away from the other was most challenging. Barriers for social interchange and engagement in participation that were perceived by all participants were not being approached actively by others: and being pressed to react timely. One adolescent [P5] described the effort that it took him to talk and how hurt he was when others interrupted him. In general, tension arose when adolescents felt overstrained by the approaches of others or when they got the impression that their reaction to an approach was wrong. The following quote shows how quickly such tension can arise:

*«At the moment somebody replied, "I don't understand?" I became immediately insecure and doubted my capabilities. What mistake did I make? Did I not explain it well enough?»* [P5].

*Becoming a group member*, the second subtheme, refers to the benefits of regular, well-organized groups in providing a venue for social interaction. Clear rules provide ease to adolescents with ASD, as exemplified by volleyball, in which there are lots of regulations, including the standing positions. For some participants, group work that was offered in vocational settings was a facilitator to start getting to know others [P2,P4,P6]. However, for one participant, group work was overwhelming [P5]. While talking in social situations was considered difficult, performing activities alongside others was perceived to be easier. Some adolescents explained that they started engagement without speaking. Informal or large groups as well as quick conversations were considered barriers to social interaction. The fact that they were engaging with their surroundings internally, but were unable to show this externally, which is easily misinterpreted as a sign of non-interest or absence, was described as a ‘tension’.

*Being acknowledged and gently guided* is the third and last subtheme of the second main theme ‘social interaction and engagement’. It combines other peoples’ acknowledgement of the presence and slightly different needs of these adolescents and of the challenges they face in a particular environment on the one hand, and gentle support or guidance being offered to them on the other. A positive affirmation (e.g. “good to see you here”), for example, facilitates participation. For instance, one participant [P6] mentioned that he felt acknowledged by receiving a disability allowance at the university, allowed him to reserve a seat in the auditorium. Most adolescents with ASD expressed fear of being stigmatized as being weird or stupid. It is therefore understandable that they found it supporting to get gentle real time advice on how to behave according to expectations as explained in the following quote and illustrated with Figure 3.7.

**Figure 3.7** “A reception that I attended with my mom”, data retrieved on Wednesday September 20th, 2017, 19:17.



*«I like when people gently tell me what I have to do in such a situation. Somebody proposed me to sit behind a table. It would be perfectly okay..... I like when they do such proposals and tell me what I should do in a gently way. I didn't know that it is decent to sit in receptions» [P5].*

Only one adolescent preferred “tougher” feedback, pointing out his weaknesses and instances in which he did not pick up on reactions, as it broadened his awareness [P5]. To all the others, even minor negative responses could turn a facilitator into a tension, as explained by one participant about his experiences in work shadowing in a kitchen [P1]:

*«I had to hack a box of parsley, and they did it mega [extremely] fast ...I stressed myself mega and still needed more time as them..... It was already a powder and they asked me to make it still smaller. I tried so hard but at the end they just said “not bad”. I was a bit glad about my result, but I don't know why they could not acknowledge my hard work and good performance.» [P1].*

After this experience the participant decided that he was not interested in working in a professional kitchen anymore.

Social encounters were strenuous for adolescents with ASD. They struggled to understand the social processes that occurred during social interchange and engagement. A quote from one adolescent [P5] explained his dilemma with greeting neighbors in the garden:

*«Before, I did not say hello. Later, I started saying hello all the time. Now I think there are fine rules I don't know, and I think a lot about them. Should I greet him immediately when I see him? Or when he looks at me? Or when he is close? How close? Do I disturb him? I feel disturbed when I am greeted. Why does he not feel that way? Or does he? How can I know?» [P5].*

Overall, social participation was rarely relaxing and joyful for adolescents with ASD.

## DISCUSSION

The goal of this study was to find out how and why adolescents with ASD perceive aspects of their environment as facilitators or barriers to their attendance and involvement in activities outside of home and school. We found that participants experienced each of these participation experiences as a social act. Two main themes were found to be paramount to achieve participation: first, five environmental prerequisites are necessary to achieve attendance of adolescents with ASD in activities: (1) the company of trusted persons, (2) the presence of a nudging drive, (3) the provision of knowledge and information, (4) the presence of good vibes, and (5) a certain design of the physical environment. Secondly, we found three environmental strategies to achieve involvement and social engagement, after attendance is achieved: (1) being approached, (2) becoming a group member, and (3) being acknowledged and gently guided. These two main themes in effect provide new insights concerning participation of adolescents, as they provide the first realistic example of the consecutive processes of the attendance and engagement of adolescents with ASD as described by Imms et al.<sup>7</sup> Both main themes describe environmental conditions for participation of adolescents with ASD in a new manner.

In this section, we further discuss (the implications of) the findings, focusing on the 3 most important subthemes, two belonging to the theme *environmental pre-requisites to attend activities*, and one to the theme *involvement and social engagement*.

The company of trusted persons was one of the most important environmental prerequisites that influenced attendance. Participants in this study were heavily dependent on family members for company and experienced joy in sharing activities with them. This result is in line with studies on children with physical disabilities.<sup>46,47</sup> Our results show that adolescents with ASD consider family support to be the most meaningful environmental aspect, in contrast to the results of an earlier study

conducted among adolescents with different kinds of disability which show that this group of people consider authentic friendships, role models, and opportunities to participate to be equally as meaningful.<sup>12</sup> Also, Kramer et al.<sup>11</sup> show that in the developmental phase of adolescence, youth normally replace the company of family with peers, but adolescents with ASD consider doing this much less or not at all. And where other adolescents value the quality of participation based on engaging alongside peers,<sup>11</sup> the adolescents in this study valued being alongside trusted persons, especially family members.

In the context of the canton of Zurich, hardly any service targets the participation of adolescents with ASD outside of home and school. Support depends heavily on family resources like time and finances. However, limited time, or financial, motivational or stigmatized restraints may result in a lack of family engagement.<sup>48,49</sup> Furthermore, spending a lot of time with family might limit participation alongside peers. To relieve families, a widening companionship provided by other confidential and trusted persons, like relatives, peers, or service staff, seems to be essential to support participation of adolescents with ASD outside of the home and outside of school. In the field of work participation, companionship is recommended<sup>50,51</sup> which is implemented successfully in the canton of Zurich considering work participation but not in other fields.

Another factor that was found to be central for the attendance of adolescents with ASD in activities outside of home and school, is the *provision of knowledge and information*. This factor concerns orientation and preparedness, which, as cognitive maps, both provide informative security.<sup>13,14</sup> However, information and knowledge are not the same. 'Information' refers to facts which are organized to describe situations or conditions. They are (or can be) made explicit and represented - seen in a philosophical way - outside of the mind.<sup>52</sup> This explicitness provides adolescents with ASD with security. Visual maps, written out train schedules and clear signage at stations are examples of (explicitly represented) information. Contrary to 'information', 'knowledge' refers to beliefs, perspectives, judgements, know-how and methodologies.<sup>52</sup> Although it is based on information, it comprises experiences of activities and social interactions and is seen by social scientists as being socially constructed. Due to the social communication problems, which are inherent to ASD, this social construction of knowledge seems specifically difficult for adolescents with ASD. In turn, this difficulty might be one of the reasons why persons with ASD often

indicate that they feel that others stereotype them as being “weird or stupid”,<sup>53</sup> as they feel a lack of knowledge or insight. For adolescents in this study, using public transport was an overall pleasant experience. Pupils in the canton of Zurich are obligatorily trained to use the public transport system, which provides a reliable traffic environment, promotes a favorable attitude towards independent travel, and is adapted to young passengers.<sup>54</sup> Participants’ attitudes towards independent travel (for school as well as for work and leisure) and their independence have greatly improved as a result of having gained knowledge. In addition, parents of Swiss adolescents with ASD are relieved from daily driving tasks. This situation would not have been possible without an approach concerning city planning and policy making that is specifically oriented towards independent travel.

As all adolescents with ASD mentioned their wish to be approached several times within one interview, we interpreted 'being approached' as the most important subtheme concerning 'involvement and social engagement'. Our study indicates that adolescents with ASD experienced the adversity of social interactions as the primary issue concerning active involvement in activities. Instead of teaching these adolescents how to approach others,<sup>55,56</sup> which is currently a common practice, but poorly facilitates generalization into natural contexts, this study offers an interactional solution, in line with Sirota.<sup>57</sup> Namely, active participation in a reciprocal social world, in which adolescents with ASD are approached, prompted and gently guided. A pro-social attitude, similar to a family’s natural behavior of questioning children with ASD during mealtime,<sup>58</sup> is needed in larger social circles. Unfortunately, although people without ASD generally do not experience difficulties in initiating conversations, they currently do not seem to do so regularly with adolescents with ASD. It is therefore recommended that more awareness about this need is created among the public at large. In addition, negative attitudes towards autism<sup>59</sup> are frequently reported and these might be softened by an increase in knowledge and awareness about the subject as well.<sup>60,61</sup> A less medicalized perception of autism, as pursued by some autism-friendly companies, might be another way to achieve more positive attitudes.<sup>49</sup>

## CHALLENGES AND LIMITATIONS

The strength of this study lies in the use of a case study design with the canton of Zurich as concrete case. The case study design fits our research objective and enables the examination of environment, hardly described for autism.<sup>59</sup> As strongly supported

by others,<sup>7,9</sup> participation occurs within a contextualized setting and participation outside of home and school can be contextually bounded.

In contrast to what was done in other studies<sup>3,62</sup> we deliberately bypassed the word 'community', as a clear definition and common understanding of this term does not exist. It is often used to refer to different entities, such as neighborhood, religious community, living area, quarter, internet community, region. In addition, no single word exists in German that conveys the same as the term 'community'. We therefore decided to use the term 'outside of home and school'. Indeed, participants understood that this term included participation in public places like cinema, sport arenas, public transport as well as visiting friends or relatives in private homes. Therefore, we recommend using this term for further studies.

As a research population, adolescents with ASD are hard-to-reach.<sup>63,64</sup> They hesitate to participate in new activities, and they need the support of trusted persons to continue. Two female participants left the study because they lacked such support. Despite recruitment support from thirty-eight key persons, the number of participants was low. It is not enough to simply ask adolescents with ASD to participate. Knowledge about the environmental prerequisites (first main theme) should be applied to assure attendance of adolescents with ASD in research projects. We recommend that consideration be given to 'company of trusted persons', 'the presence of a nudging drive', and 'provision of knowledge and information' when conducting future research projects that include adolescents with ASD, if needed by employing assistants. This would benefit both future research projects as well as participating adolescents with ASD as they were keen to have their voices heard and felt proud to succeed participating in a research project.<sup>63</sup>

Given the small sample size, our results cannot be generalized to the broader population of adolescents with ASD. The sample did, however, provide us with a rich amount of data with consisting of 69 photos and nearly 13 hours of interviews. Since our data was exclusively provided by male participants, results might not be fully transferrable to the experiences of female adolescents with ASD, as they tend to participate in different environments and activities, to interact with different people, and have different communication styles than males.<sup>65,66</sup> In addition, our inclusion criterium of needing to participate in at least one activity without company, might mean that our results do not fully apply to adolescents with severe language or cognitive impairments, as they might be influenced by other environmental aspects as well.

Photo-elicitation is an established method for conducting studies among persons in the autistic spectrum.<sup>44,67</sup> Using this method is appropriate for such studies as it allows people with ASD to engage with something visually, which is what they are generally good at. On the other hand, however, the use of photo-elicitation in this study did have some additional (unintended) side effects. First, the participants hardly took any pictures of people. Second, understandably, no photos were taken in environments the participants felt altogether too uncomfortable to attend in the first place (leading to very few barriers being described). These shortcomings, especially the second, are likely a result of participants' ASD and should be taken into account in future research among this population.<sup>4</sup>

## DIRECTIONS FOR FUTURE PRACTICE AND RESEARCH

If the canton of Zurich and other geographical regions want to enhance the societal participation of adolescents with ASD, the creation of more autism-friendly environments is essential, just as environmental interventions are prioritized for other youths with disabilities.<sup>68,69</sup> More concretely, services and governments could address the environmental need of people with ASD for company, knowledge and information and positive vibes in social environments. Furthermore, a campaign to inform the general public of how adolescents with ASD can be included is recommended. Although set up by an individual entrepreneur, the website by Janneke Koekhoven serves as a fine example for such campaigns.<sup>70</sup>

Further research should explore the extent to which different environmental features support the participation of adolescents with ASD and which environmental changes are needed. Which changes are most conducive to improvement, might differ from country to country, depending on the social, economic, healthcare and welfare situations that exist. Additionally, successful strategies that can be employed by parents to make social environments more attractive for their adolescent children with ASD need to be further explored and systematically described, in order to achieve attendance and involvement in participation.



## CONCLUSIONS

This study, focusing on the case of Zurich, Switzerland, provides unique context-bound insight into two aspects of the way in which and the reasons why environments influence the participation of adolescents with ASD outside of the home and school. While the first main theme concerns environmental prerequisites that promote attendance, the second main theme concerns reciprocal strategies to initiate or increase the social involvement of adolescents with ASD. The influence of trusted persons for the participation of adolescents with ASD is highlighted, combined with a plea to relieve these trusted persons through broadening the support network to peers, services, and the society in general.

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# CHAPTER 4

Cross-cultural adaptation of the Participation and  
Environment Measure for Children and Youth  
(PEM-CY) into German: a qualitative study  
in three countries



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*BMC Pediatrics* 2020;20(1):492

## ABSTRACT

### **Background**

Concepts such as participation and environment may differ across cultures. Consequently, to use a measure like the Participation and Environment Measure for Children and Youth (PEM-CY) in other than the original English-speaking contexts, cultural adaptation needs to be assured. The aim of this study was to cross-culturally translate and adapt the PEM-CY into German as it is used in Germany, Austria and Switzerland.

### **Methods**

Fifteen parents of children and adolescents with disabilities from three German speaking countries participated in three rounds of think-aloud interviews. We followed the procedure of cultural equivalence guidelines including two additional steps. Data was analyzed by content analysis using semantic, idiomatic, experiential and conceptual equivalence.

### **Results**

Results show adaptations mainly focused on experiential and conceptual equivalence, with conceptual equivalence being the most challenging to reach. Examples of experiential equivalence included adapting the examples of activities in the PEM-CY to reflect those typical in German speaking countries. Conceptual equivalence mainly addressed aspects of “involvement” and “environment” of children and adolescents and was reached through adaptations such as enhanced instructions and structures, and additional definitions.

### **Conclusion**

This study presents a cross-cultural translation and adaptation process to develop a German version of the PEM-CY that is suitable for Germany, Austria and Switzerland. Using a modified cultural adaptation process, a culturally adapted version of PEM-CY (German) is now available for research, practice and further validation.



## BACKGROUND

Concepts such as “*participation*” and “*the environment*” may differ across cultures.<sup>1</sup> Yet, when the World Health Organization (WHO) included these terms in the International Classification of Function, Disability and Health (ICF), the intention was to address these complex health phenomena universally for adults, children and youth.<sup>2,3</sup> Participation defined as ‘*involvement in life situations*’<sup>2</sup> is an important outcome for rehabilitation in adults and youth.<sup>4–6</sup> Environment defined as, “*the physical, social, and attitudinal environment in which people live and conduct their lives*”<sup>2,3</sup> has gained importance as a factor that can be targeted by rehabilitation interventions.<sup>7,8</sup> Within the global use of ICF concepts, different cultures and societies shape how “participation” and “environment” are experienced concretely in real life. As such, related assessments should be used universally<sup>9</sup> and at the same time reflect cultural values. However, many commonly used assessments are developed in English speaking regions such as North America or Australia<sup>10,11</sup> and might not be culturally suitable in other countries. These differences have to be looked at for each region and language separately. For example, participating in football may not have the same meaning in North America as in Europe and these types of differences should be reflected in internationally used instruments.

Culture has been defined as the “total shared, learned behavior of a society or a subgroup”.<sup>12[p22]</sup> Direct translation of an assessment without proper cultural adaptation may leave gathered data unfit for proper interpretation.<sup>13</sup> Specifically for participation assessments, a lack of cultural equivalence in the translated measure has been reported.<sup>14</sup> As conceptualization of participation may vary across cultures, the translation of assessments needs to be combined with cross-cultural adaptation.<sup>15,16</sup> In addition, language can have a significant influence on thoughts<sup>17</sup> and it is therefore important to gain insight into end-user’s understanding when filling in an internationally translated and culturally adapted assessment.

The Participation and Environment Measure – Children and Youth (PEM-CY)<sup>18</sup> is one of few assessments that combines the measurement of participation and environment for children and youth. It is a standardized parent-reported assessment to determine the extent and pattern of participation of children and youth aged 5-17 years, their levels of participation, involvement, related environmental barriers and supports, and parental wishes for changes in participation. Informed by results of qualitative interviews with parents,<sup>19</sup> the PEM-CY was tested primarily with 576 parents of children with and without disability from Canada and the USA<sup>18</sup> and was found to have

moderate to good reliability and validity. The PEM-CY has been used to measure participation of children with specific diagnoses, such as unilateral cerebral palsy<sup>20</sup> and autism spectrum disorder,<sup>21</sup> to compare participation of children with different disabilities<sup>22</sup> and between different settings such as home, school and community<sup>23</sup>. The PEM-CY has been translated and culturally adapted into a number of languages, including Korean,<sup>16</sup> Chinese,<sup>24</sup> Icelandic,<sup>21</sup> Hindi (Roopa Srinivasan, personal communication), Dutch (Eftje Kern, personal communication), and Flemish (Mareike Coussens, personal communications).

A German translation of the PEM-CY was developed in Austria<sup>25</sup>. After investigating reliability and validity of this translated version, the author concluded that it should be culturally adapted to better fit the Austrian context (“specifically school and leisure activities” <sup>25(p155)</sup> and to improve the comprehension of items, as this might have been the reason for low reliability rates.<sup>25</sup> In German speaking Switzerland,<sup>26</sup> a revision of the format was suggested to improve “ease of comprehension and improved cultural applicability”.<sup>25(p67)</sup> Thus, problems with reliability, face validity and cultural applicability in two German speaking countries have been identified.<sup>26</sup>

To the best of our knowledge, other than the PEM-CY, no other measurement is available in German to assess child and youth participation and their respective environments. German is mainly spoken in Central Europe and is the native language to almost 100 million people. It is the official or co-official language in Germany, Austria, Switzerland, Lichtenstein, and in the German speaking communities in South Tyrol (Italy), Belgium, Luxembourg, and Poland. However, different regions use different dialects and words, or phrases used in one country are not understood or differ in meaning in another one. This was the main barrier to using the Austrian Version of PEM-CY<sup>25</sup> with German speaking parents in Switzerland.<sup>26</sup> As health professionals in these countries work closely together and worker mobility is high, common assessments are needed. Thus, the rationale for this study is that a valid cross-cultural adaptation of the PEM-CY into German is needed, taking into account that the questionnaire should be adapted and understandable for all German-speaking regions. The aim of this study was to cross-culturally translate and adapt the PEM-CY into German in a way that culturally represents the PEM-CY constructs of “participation” and “environment” in Switzerland, Germany, and Austria. We formulated the following research question: *What changes are needed to reach cross-cultural equivalence of the PEM-CY in German as spoken in Germany, Austria, and Switzerland?*

## METHOD

### DESIGN

Cross-cultural adaptation “encompasses a process which looks at both language (translation) and cultural adaptation issues in the process of preparing a questionnaire for use in another setting” [page 3].<sup>27</sup> To translate and adapt the PEM-CY into German, we applied international standards and established guidelines<sup>28</sup> which aim “to produce equivalency between source and target, based on content” [page 3186]. This six-step process includes forward and back translations, synthesis by an inter-professional expert team and pilot testing with parents.<sup>28</sup> To enhance the process, we added: ongoing discussion with developers (represented by the PEM-CY team from CanChild) and a final back translation. The expert committee consisted of occupational therapists from Germany, Switzerland, and Austria with experience in childhood disabilities (BK, CS, RA, JB), health care methodologists (BP, AM, AB), a professional linguist and two English native speaking non-health professionals. A translation agreement was signed between CanChild/McMaster University and the expert committee.

### SETTING

This study took place within the state-supported health care and federally organized educational systems in Germany, Austria, and Switzerland. All three countries aim to include children with special needs in mainstream schools, as recommended by the Salamanca declaration of UNESCO<sup>29</sup>. Specialized teachers and assistants provide support in the classrooms as required. Children attend Kindergarten before entering school at age 6 or 7, followed by an apprenticeship at age 15. However, due to the different national political systems, there are slight differences in regulations influencing school and health services.

### PARTICIPANTS AND ETHICS

Fifteen parents of children with disabilities participated in this study. Criteria for inclusion were: 1) being responsible for a child between 5 and 17 years of age with a disability, 2) living in Germany, Austria, or Switzerland in the last 5 years, and 3) able to read and speak German. Parents were recruited from the work settings of the participating experts. A purposeful sampling technique was used to reach diversity. Sampling was conducted in three rounds (see Figure 4.1). Participating parents were

provided with detailed information on the study in both written and verbal formats, and they voluntarily consented to their own participation and also on behalf of their children whose data was collected but was not the focus of analysis. Table 4.1 describes the characteristics of the sample.

**Table 4.1** List of Participants of three rounds of cognitive interviews.

Interview	Characteristics of parents					Characteristics of children			
	Round	Parenting role	Age	Education	Profession	Age	Gender	Medical diagnosis	School
Germany	1	mother	34	middle	medical assistant	8	female	Trisomy 21	mainstream
	1	mother	40	middle	nurse	11	male	Visual impairment	mainstream
	1	mother	35	middle	OT	7	female	Sigmatism swallow disorder	mainstream
	2	mother	34	low	florist	12	male	ADHD	mainstream
	1	grand-mother	57	middle	retired	6	male	ADHD	mainstream
Austria	1	mother	45	high	economist	7	male	DCD	mainstream
	2	mother	45	middle	at home cleaner	16	male	CP	special school
	3	mother	46	high	tax adviser	6	female	Fanconi anaemia	special kindergarten
	3	mother	42	high	university assistant	8	female	Mukopolysacceri-dosis	special school
Switzerland	1	mother	37	middle	secretary	9	male	DCD	mainstream
	1	mother	35	middle	administrator	8	female	CP	mainstream
	2	father	40	middle	caregiver	13	male	ASD	mainstream
	2	mother	45	middle	secretary	17	female	Arthrogryphosis	Internship and special school
	3	mother	54	high	economist	15	male	ASD	boarding school
	3	father	31	low	mechanic	5	male	ASD	mainstream
		mother	35	low	cleaner				kindergarten

## PROCEDURES (DELINEATED IN FIGURE 4.1)

### *Stage I: Forward translation*

Following the guidelines,<sup>28</sup> we started with two forward translations of the English PEM-CY into German. One of the translations (T1) was the existing translation conducted by an informed health scientist in Austria<sup>25</sup> and the second translation (T2) was prepared by a professional translator not familiar with the PEM-CY. During this stage, the cultural adaptation process focused on idiomatic and semantic equivalence.

*Stage II: Synthesis 1*

The expert committee compared these two translations to develop one synthesized version (T3). The focus was on ensuring comprehension of the wording in all three countries. Activities that required cultural adaptation were identified and agreed upon.

*Stage III: Back-translation*

To “avoid information bias and elicit unexpected meaning”,<sup>30(p3188)</sup> two individuals with native English, translated the synthesized version (T3) back into English (BT1 and BT2). Both translators were blinded to the original PEM-CY version, had no medical background and were fluent in German.

*Stage IV: Expert committee review*

The expert committee compared BT1 and BT2 with the original PEM-CY to identify and discuss differences between the two back-translations. We considered English synonyms (such as “caring for household pets” versus “looking after pets”), differences in wording with different meaning in German (such as “community”) and differences that occurred due to cultural adaptations of activities (such as “baseball” versus “soccer”). All unresolved differences were discussed with the PEM-CY team from CanChild who provided advice on the specific discrepancies. Next, a linguist looked at comprehension for all three German speaking countries and provided feedback on T3. All of this feedback lead to the Pre-final Version 1.

*Stage V: Tests of the pre-final versions*

Pre-final Version 1 was tested with concurrent think-aloud interviews<sup>31,32</sup> using a 3-step procedure<sup>33</sup> with seven parents of children between the age of 5-11 years. The first step included observation and listening to their thoughts, the second step involved probing and the third step focused on debriefing and recommended changes. This enabled us to assess unique higher-level thinking processes, while identifying individual differences in task performance.<sup>34</sup> An interview guide and personal briefing of interviewers assured a similar process in all three countries. Once themes identifying the need for changes emerged recurrently, we stopped the first round of interviews and the expert team started the analysis (see section below for details). Parent performance and suggestions for the improvements were the focus of reflection and analysis. Recommended changes were then discussed and agreed upon with CanChild.

Pre-final Version 2 was then used in a second round of interviews with parents of adolescents. Following the analysis, expert review, and consultation with CanChild, we developed Pre-final Version 3 and used it to conduct retrospective cognitive interviews, in which four parents filled in the questionnaire while being observed without interruptions. The parents were then interviewed about problems, moments of hesitation and comments in general. This process was used as we expected less need for changes at this stage. Further discussion and analysis of the data led to a consensus, resulting in the PEM-CY (German) (Pre-final Version 4).

*Stage VI: Submission of the PEM-CY (German) proposal*

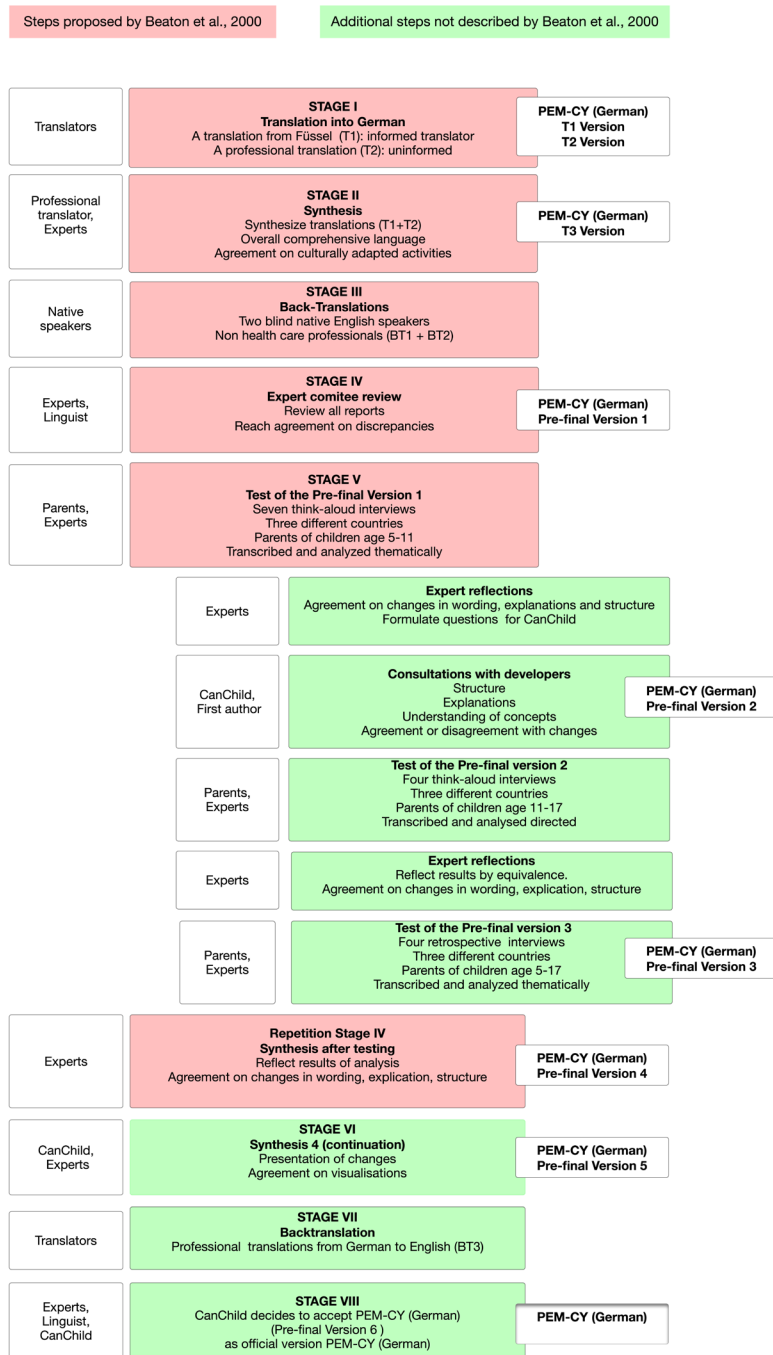
The expert team discussed the Pre-final Version 4 with the PEM-CY team from CanChild. Although some of the proposed structural changes were not accepted by the CanChild team, other improvements led to the PEM-CY (German) Pre-final Version 5. The CanChild team requested an additional back translation to fully review and approve all changes.

*Stage VII: Back translation*

A back translation of PEM-CY (German) Pre-final Version 5 was performed by a professional translator (BT3).

*Stage VIII Final agreement*

All changes were discussed with team from CanChild. The linguist checked the text and made revisions (Pre-final Version 6), leading to the final version of the PEM-CY (German).

**Figure 4.1** Process of cross-cultural adaptation of PEM-CY to PEM-CY (German).

## ANALYSIS

The data for this study included verbatim transcriptions of the cognitive interviews, interview observation notes and minutes of all experts' meetings. We used a directed content analysis,<sup>35</sup> applying a-priori set of codes to search for common patterns in the data. This was guided by four types of equivalence.<sup>28</sup> Semantic equivalence (1) refers to the use of words that mean the same. For example, we analyzed how parents understood and explained words such as "participation" or "involvement". Idiomatic equivalence (2) includes colloquialisms and idioms, such as "hanging out", that may lack or have a different meaning across cultures and therefore require re-phrasing. (3) Experiential equivalence seeks to replace items with those capturing the same life experiences in another culture. This included inserting culturally relevant activities, proposed by the experts. Finally, (4) conceptual equivalence refers to concepts that linguistically cover the same logic, meaning or mental images associated with a word or phrase when transferred to another culture. We analyzed for example, how parents understood and interpreted the concepts such as "home" or the general structure of the questions used in the PEM-CY. After the first author coded changes in all four types of equivalence, part of the expert team repeated some of the analysis. Subsequently, all experts discussed the judgements consecutively, until consensus was reached on changes made to each version (see Table 4.2).

## TRUSTWORTHINESS

Experts from three German speaking countries were involved in all phases and ensured researcher triangulation.<sup>36,37</sup> Four kinds of data (translations, expert knowledge, observations and transcripts) ensured data triangulation. In the last round of interviews, participants tested the final version and provided feedback on it. To ensure transferability, we provided a thick description of the research process and data collection, including quotes from the interviews.

## RESULTS

Results focused on the research question, *"What changes are needed to reach cross-cultural equivalence of the PEM-CY in German as spoken in the three countries?"*, are presented in two tables. Table 4.2 presents the type of changes made during the pre-final versions 1 to 6, which are organized and explained according to the four types of



equivalences in Table 4.3. We illustrate each type of equivalence with quotes taken from the transcribed interviews and examples from field observations made while parents completed the Pre-final Versions 1-3 of PEM-CY (German).

**Table 4.2 Development of equivalence (Version 1-6).**

Stage	Original	Equivalence				Changes made and cultural adaptations	
	Version PEM-CY	PEM-CY (English)	semantic	idiomatic	experiential	conceptual	PEM-CY (G) (German)
STAGE I	Translation (T1/T2)	gender		x			removal of gender nomenclating for child (her or she)
		wording (e.g. "environment")	x				use of different words (synonyms) e.g. environment (G: "Umfeld", "Umwelt")
		wording (e.g. "community", "involvement")	x				lack of direct translation into German e.g. "community (G: "gesellschaftlich" "gemeinschaftlich") involvement ("beteiligt" versus "engagiert")
		wording (e.g. school lunch)		x			country specific wordings e.g. "Jause"(Austria) versus "Vesper"(Germany), "Znüni"(Switzerland)
STAGE II	Synthesis (T3)	wording (e.g. assignments, lunch preparation) "involvement"	x				agreement to choose words commonly used in all three countries e.g. (G: "Hausaufgaben", "Essen zubereiten") agreement on "being part and involved" (G. "beteiligt und eingebunden sein")
		activities			x		removal of activities that are not typical in German speaking countries (e.g. public speaking") addition of cultural adapted activities, e.g. "soccer", "learning vocabulary"
		structure				x	present environment questions 8 (9) on next page
STAGE IV	Pre-final 1	general wording	x				small changes in used language structure, e.g. change from survey to "questionnaire" (G: "Fragebogen")
		response item	x				revised "not an issue" (G: "nicht relevant")

**Table 4.2** (continued)

Following first round of interviews (#1 - #7)							
STAGE IV	Pre-final 2	introduction				x	adapt introduction - add age range of PEM-CY (5-17 years) - explain “participation” and “environment” - add a sentence that that this survey is not about the child’s independence - express that activities are just examples
		explanations				x	add encouragement for parents to fill in school setting
		sequences				x	change sequence of activity groups, start with “Indoor play and games”
		response items				x	x for school setting, add “on school days” repeat the 4 month timeframe of frequency on each page insert a 2 phase response option to all environmental parts: “No, it is no issue”, “yes it is an issue” and then explain supportiveness.
		“demands”				x	insert “demands and expectations” to questions 4-6 in environments
		“involvement”					change of German word for “involvement” (G: “Engagement”) (see stage II)
		structure				x	add subtitles to A (frequency), B (involvement), C (wished changes) add line for comments (voluntary) for all activity groups
Following second round of interviews (#8 - #11)							
STAGE V	Pre-final 3	“child”	x				use whenever possible “child and adolescent”
		“neighborhoods”					replaced by “visits to public areas”
		explanations				x	present a definition of home, school and community on each page
		response items				x	inserted a note that parents should think broadly about the environment sections
		environment					change the answer format: headline (A and B answers) and subtheme (B1, B2, B3) referring to hindering and supportive environments
Following third round of interviews (#12 -#15)							
STAGE IV	Pre-final 4	“school”				x	add “school and kindergarten”
		visualization				x	visually structure the item “wished changes” with a thicker line highlight “skip to C”
STAGE V	Pre-final 5	explanations				x	explaining that garden or yard is part of home explaining that way to school is part of school
		“demands”				x	remove “expectations” (see stage IV)
		structure				x	remove proposed structure (see Stage V) and verbalize supporting and hindering environment (see figure 4.2)

The Pre-final Version 6, after the backtranslation and grammar check by linguist, became the final version (see Table 4.3)

**Table 4.3** Synthesis of needed equivalence changes to develop the PEM-CY (German).

Equivalent changes	Explanation	Original PEM-CY	Changes made to culturally adapt the PEM-CY (German)
Semantic equivalence	A similar semantic expression	“community” “involvement” “participation” “children	“societal” (G: gesellschaftlich) “engagement” (G: “Engagement”) “participation” G: “Teilhabe” “children and adolescents” (G: “Kinder und Jugendliche”) neutral form (it) (“G: “es”)
Idiomatic equivalence	Less misleading expression	“the child”- he or she “assignment” and “homework” “climate”	“homework and assignments” (G: “Hausaufgaben”) “seasonal conditions” (G: “Jahreszeiten”)
Experiential equivalence	Words that represent culturally based experiences	activity examples used in the original PEM-CY that are not common for children in the targeted countries: “Brownies”, “mentoring”, “lunchroom supervisor”, “public speaking”, “working in a store”, “baseball” “Video gaming” is the first group of activities in the home setting school participation: response option “daily” school participation “neighborhood”	removed uncommon examples and added new examples: “playing Lego”, “showering”, “learning vocabulary”, “going to school”, “bullying and misuse”, “soccer”, “skiing”, “walking”, “salary during apprenticeship and internship”. “Video gaming” moved and is now the third group of activities in the home setting school participation – response option changed to “daily at school days” kindergarten and school participation “visits in public area”
Conceptual equivalence	Covering linguistically the same logic, meaning or mental images		Additional information: enhanced definition of “participation” and “environment” added information about the possible age of children (5-17 years) explained that it is not about independence included the time frame of four months on each page added encouragement to fill in school setting despite little knowledge instructed global thinking in the “environmental sections” provided examples for all environmental items Structural changes: add headings for all participation aspects (frequency, involvement, desire for change) insert “activity group” as subheading make thicker lines between options for wishes for changes highlight “Skip to C” explain environment and settings on each page repetition of “environmental factor” in possible answers present all questions with the same answer format in the environment part on the same page. added line for possible comments for desired changes in participation

## SEMANTIC EQUIVALENCE

Overall, the four words “participation”, “involvement”, “community” and “children” could not be simply translated and needed in-depth discussion between the linguists and the expert team. These words were tested and discussed with end-users during the cognitive interviews. Given the importance of each of these words to the PEM-CY, the resulting changes are discussed below.

For “participation”, two German words exist. An equivalent of “to take part” (G: “teilnehmen”) and a more complex, less common word “to participate” (G: “teilhaben”), used mainly in professional language. Parents often read “teilnehmen” where “teilhaben” was written. Despite expressing unfamiliarity with the word “teilhaben”, they preferred it for its’ deeper meaning. Therefore, “teilhaben” is used in the adapted PEM-CY (German).

One mother mentioned a problem when judging her child’s participation and the inherent cultural norms related to inclusive programs:

*“...should I judge whether she takes part with healthy children or with other children with disabilities? I have to confess that my daughter hardly participates in settings with healthy children. Either she is accompanied by us, or she participates in activities that are geared for children with disabilities. Like swimming. If she is expected to participate in swimming here in the town, regularly, the answers would be completely different.” [P#13]*

The word “involvement” presented a different challenge. It is a multifaceted concept for which no single German translation exists. One mother explained some difficulties in judging her child’s involvement:

*«The word «independence» would have fit better to our situation. Yes, he can do everything, he just has to be reminded. Sometimes, he goes shopping for me or picks up apples at a farm [...] How involved he is? I don’t know. He makes it for me, but if he would not be obliged to do it, he would do something else. But when he does it, he is reliable, everything is perfect, he can handle the money and he behaves decently. For involvement I consider his joy and his motivation. He may not have it, but nevertheless, he performs well.” [P#2]*

This mother added that observing independence is easier than observing involvement. Most parents mentioned motivation in connection with involvement. Some spoke about an inner process of being present and active. Others connected it with being interested, curious and open. One mother mentioned that involvement also depends on others.

*“It means he takes part actively, but he also has to be accepted by others.” [P#5]*

These aspects could not be transferred directly into one German word. After the second round of interviews, we consulted with the linguist and agreed upon “engagement” (German (G): “Engagement”) and “being engaged” (G: “engagiert sein”). Revisions for the two additional words, “community” and “children”, were more straightforward. As there was no direct translation for “community”, we selected “societal” (German “gesellschaftlich”) as the best alternative to refer to any public space or social entity outside the home and school. Finally, the PEM-CY directions uses the word “children” to apply to ages 5 to 17 years. In German, children over the age of 14 are called “adolescents” (G: “Jugendliche”). Similar to the “Y” for “youth” in the title PEM-CY, “adolescents” needed to be mentioned throughout the measure.

## IDIOMATIC EQUIVALENCE

Three changes could be interpreted as belonging to this category. First, in the English version, “child” is always referred to as he/she. As “child” in German is neutral (“das Kind”), we did not need to use gender differences. Secondly, the expert committee agreed to use one single word (G: “Hausaufgaben”) for all school-tasks done at home (E: “homework” and “assignments”). Thirdly, some parents were confused by the word “climate” when translated into German, and its’ relevance at school.

*«Weather condition, climate? <laughs> ...This does not make sense. Climate at school? I don’t question this. I presume that there is enough light and enough heating and no rain in the classroom.» [P#6]*

We therefore chose the wording “seasonal conditions” (G: “Jahreszeiten”) to align with the original meaning of outdoor climate.

## EXPERIENTIAL EQUIVALENCE

To capture the different cultural experiences, several examples for activities from the original PEM-CY were removed from the German version. Examples of these include “mentoring”, acting as “lunchroom supervisor”, “public speaking”, “working in a store”, being a “Brownie”, and playing “baseball”. Although these activities are known in German speaking contexts, they do not have the same cultural importance to serve as examples in the PEM-CY (German). The experts agreed on more typical cultural activities such as “playing Lego®”, “showering”, “learning vocabulary”, “going to school”, “bullying and misuse”, playing “soccer”, “skiing”, “walking” and receiving “salary during

apprenticeship and internship”. Parents did not raise any concerns with the proposed activities. However, some were surprised that “computer and video games” was the first activity mentioned in the home setting.

*«My child is 6 years of age. I am proud that video gaming is an activity he did not yet discover. But I am rather astonished to see it here as the first listed activity.»*

[P#5]

To address parent concerns, “computer and video games” was moved to the third item in the home setting in the PEM-CY (German).

In the school setting, parents rarely chose the option “daily” for participation frequency because their children were not attending school on weekends. We therefore changed it from “daily” to “daily on school days”. As school starts in German-speaking countries generally at 6 or 7 years of age, we added the word “kindergarten” in the school section, to include 5 year-old children.

In the community setting, a mother indicated that her daughter with arthrogryposis never participates in neighborhood outings like shopping or going to a movie.

*«If you skip the word “neighborhood”, I would answer this question totally different. My daughter is 17 years, she uses public mobility and accesses with her scooter, malls and cinemas in the city. “Neighborhood” is even not our village, it is narrower, just here, our neighbors.»* [P#13]

As such, the term ‘neighborhood’ was considered too restrictive to best reflect the equivalent idea in Germany, Austria, and Switzerland. We replaced it with the term “in public” (G: “in der Öffentlichkeit”), to be sure parents understood this to include public spaces that are beyond the immediate vicinity of the home, but within reach of public transport, for example.

## CONCEPTUAL EQUIVALENCE

To ensure conceptual equivalence of the PEM-CY (German), the expert group used three different kinds of adaptations: adding additional information, improving the visual structure and providing opportunities for parents to add comments.

Additional information was needed in various forms: first, definitions of “participation” and “environment” were added in the introduction, as parents who did not understand English missed this information and aim from the title – PEM-CY. This was also helpful as parents interpreted these concepts in many different ways, with one misinterpretation shown in the following example:

*«Participation for me is when my child does something with somebody else, thus not necessarily alone. Therefore, I have problems with the participation item “computer games”, because here he is alone. At least two persons must be involved to talk about “participation”» [P #8].*

Next, adding the age range of the assessment helped parents to understand that not all activities are suited to their child. For example, young children would not be expected to use technology for socializing. Also, as parents in the first round often mixed up “independence” and “participation”, we strongly emphasized that this assessment is not about independence. Further, the settings (home, school, and community) are explained on each page because parents were confused about separating these settings clearly. For example, parents wondered if the yard of the house was part of the home setting or already part of the community setting. Finally, parents often forgot the time frame of four months during scoring. Mentioning this on each scoring page of participation supported a more correct answering pattern.

The school setting was another area in which additional information was needed. Contrary to the home setting where parents saw themselves as a knowledgeable informant, most hesitated to fill in the school setting section. When children don't talk about school experiences, parents feel uninformed about school. It involved also cultural-aspects, as one mother reasoned:

*«I have the time to support my child at school. But this is not wished for. I could attend and bring him to activities at school. So, I could choose “yes”. Theoretically. But at the entrance of the school is a sign indicating “from here on I can do it all by myself”. We parents should not enter the school.» [P#6]*

Other parents mentioned that everything is okay as long as teachers don't complain. Therefore, an additional sentence in the PEM-CY (German) encourages parents to fill the school part out according to their knowledge gained from conversations with their child and/or teachers.

When considering the environment section, we found it supportive to add examples to all environmental questions. In the first and second round of interviews, parents had difficulties with the change of focus from the detailed participation part to the general environment part. We provided additional instructions to help them think more globally (see Figure 4.2). To further support their understanding, each item of environment was explained using examples of activities. While the original PEM-CY asks about “the physical demands of typical activities in the home (e.g., strength, endurance, coordination)”, this was changed in the German version to “the physical

demands for activities at home, referring to the strength, endurance and coordination required (e.g., during playing, dressing, cooking)”. Generally, the three items that ask about “physical, cognitive and social-communicative demands” were difficult for most participants. The mother of a girl with arthrogryposis explained:

*«When I think of emptying the dishwasher[...] it is clear that it is harder for her than for her brother. But I do not expect her to do the same as her brother. So, what are here demands? I don't understand[...] is this a requirement or demands I judge and pose on her? Of course, she removes the plastic items and not the heavy loads. I don't know what to do here. This does not make sense to me.» [P#13]*

The team from CanChild indicated that their intention was to focus on activity demands (and not expectations of others), leading to a rephrasing in German to emphasize different activities.

To improve the visual structure of the questionnaire and make it easier to complete, titles were added to the three scoring aspects of participation (frequency, involvement and change desired). This change was needed because in the first round, parents confused these aspects or did not fill them out separately. Titles made the three categories more explicit and it was easier to refer to them in the introduction. Parents also had difficulties understanding that the “activities” are just examples. We titled these activities as “activity groups” and instructed them in the introduction to choose one or two activities out of an activity group. This supported understanding. Finally, as proposed by parents, we inserted thicker lines between the different types of change desired. This was intended to help parents to stay in the correct row and mark the correct answer.

In the first round of interviews, parents also had difficulties comprehending the concept and logic based on the format of most questions in the environment section. A mother of a child with DCD for example stated:

*«I don't understand this theme «environment» quite right. I don't see a connection between activities, these questions and the provided answers. I can't answer them.» [P#10]*

Parents felt overwhelmed being asked if the environmental element is (1) an issue and if it is, (2) is it available and/or adequate and whether it is (3) supporting or hindering the child's participation. The following example illustrates how a father of a boy with autism spectrum disorder searched for an answer for the item: “The social demands of typical activities in the home (e.g., communication, interacting with others).” He read the question twice loudly and then expressed his thoughts:



«Well, here I am asked about influence. But influence does not support. I have to make a cognitive triangle here. The scale does not fit to the question, well, I guess I have to transmit the scale to demands. I imagine myself a typical situation at home at the table. My son has some difficulties with social communicative situations...what shall I choose here. Sometimes these situations make it easier, sometimes not [reads the question again]. For me this does not fit. I...I really do not get it. It always helps sometimes and makes it harder sometimes. There is never just one direction. This is somehow much too global. I stop here, maybe later I'll understand it better.» [P#12]

In addition to the item format, parents struggled with the global answer that was expected. We proposed a two-phase response option to ease these difficulties: “if it is an issue, is it helpful or does it make it harder”. This was rejected by the team from CanChild with the argument that changing to a dichotomic response may affect the psychometric properties of the assessment. Instead we agreed to insert the environmental factor into each possible answer (see Figure 4.2)

**Figure 4.2** Comparison of changes from PEM-CY to PEM-CY (G) in the Environment Section.

Original English Version

Do the following things <u>help</u> or <u>make it harder</u> for your child to participate in activities at home?	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
CHECK ONE RESPONSE <input checked="" type="checkbox"/>				

Back Translation of PEM-CY (German)

Respond to the following as generally as possible. Is this difficult for you, imagine yourself activities at home your child does often. Which influence do the following environmental factors (1-7) have on your child's participation in typical activities at home?	The environmental factor is not an issue	The environmental factor is an issue. It is mostly helpful	The environmental factor is an issue. It is sometimes helpful, sometimes hindering	The environmental factor is an issue. It is mostly hindering
CHOOSE ONE ANSWER <input checked="" type="checkbox"/>				

Although most participants found completing the PEM-CY strenuous, during the first round they wanted the opportunity to express their concrete wishes for change in their child's participation. Some started to underline the activity in which they wished to see changes. To address this, we added a column to offer parents space to voluntarily write additional comments. This seemed to improve their comfort in answering the questions, as there were only a few comments in the following rounds.

## PARENTS' SUGGESTIONS FOR ADDITIONAL PEM-CY REVISIONS

Some changes proposed by parents were beyond the cultural adaptation of the PEM-CY. For example, parents indicated that they would like to see activities in connection with sleep and restoration, and questions about planning of activities. Some proposed to make item 5 “getting together with other people” in Home participation into two separate items, one for interacting with family members and one for guests. In the environmental sections, it was suggested that insurance coverage be included, which seems specifically important for children in need of medical or technical aids and personal assistance. As these changes would have changed the nature of the measure, they were not included in the PEM-CY (German).

## DISCUSSION

The aim of this study was to translate and cross-culturally adapt the PEM-CY into German in a way that represents the PEM-CY constructs of “participation” and “environment” in Switzerland, Germany and Austria. Based on the number of changes as well as their relative importance, results show the adaptations mainly focused on experiential and conceptual equivalence and that these changes mainly occurred following the cognitive interviews with parents. For experiential equivalence, the main change was to adapt the examples of activities suggested in the PEM-CY to those that are more typical in German speaking countries. Conceptual equivalence most significantly addressed aspects of “involvement” and “environment” of children and adolescents. This was reached through adaptations, such as enhanced instructions and format, and additional definitions.

Three aspects are important to discuss further: firstly, the process that included end-users, a diverse group of investigators and developers of the measure. Secondly, the four types of equivalent changes (semantic, idiomatic, experiential and conceptual) that were necessary to culturally represent the PEM-CY in Germany, Switzerland and Austria without changing the measure’s construct. Finally, the interrelation between the two main concepts of the PEM-CY, “participation” and “environment”.

This study followed the cross-cultural adaptation guidelines by Beaton<sup>28</sup> because of their procedural clarity and broad usage.<sup>16,38,39</sup> All stages in the process were found useful and were followed. In addition, we adapted the procedure in two ways: we included the developers (PEM-CY team from CanChild) throughout the process and

added two new steps (Step 6 – Synthesis with the CanChild Team and Step 7 – Second back translation). Involving the team from CanChild ensured communication and agreement on conceptual equivalence, and ongoing developer input helped to maintain the measure's constructs. As suggested in the literature<sup>16,38</sup>, these steps prevented problems in operationalization and in obtaining normative intercultural comparison at a later stage.<sup>14,40</sup> Although pilot testing is not fully described in Beaton's guidelines,<sup>28</sup> we included a think-aloud method<sup>33</sup> with parents of children with disabilities. End-user's perspectives are often overlooked in cross-cultural adaptations.<sup>40</sup> The insights about language and comprehensiveness of the PEM-CY that were gained by the think-aloud interviews lead to major equivalent changes in our study. Similar effects are reported with the cross-cultural adaptation of another participation measure, the Pediatric Evaluation of Disability Inventory - Computer Adaptive Test (PEDI-CAT), when translated and adapted into Dutch.<sup>38</sup> Specifically, the fact that all participants were parents of children and adolescents with disabilities, challenged our perceptions and understanding of normative participation. Feedback from parents with severely disabled youth, led us to question the norms and values that typically define participation in mainstream activities. In line with family-centered care and service-user involvement in general,<sup>41</sup> we strongly recommend including end-users in future cross-cultural adaptation studies through both interviews and membership in expert committees.

To develop the PEM-CY (German), all four equivalences were used. Some of the changes were easy to address, particularly with our diverse study team. For example, idiomatic equivalence was easily addressed by the linguists. Experiential equivalence that focused on activity examples were handled by the expert team. These changes were expected based on similar processes<sup>16,42</sup> that found activities are highly variable among different cultures.<sup>43</sup> Agreeing on which activities to revise for all three countries was a straightforward adaptation. This was particularly true for the school items. Although the school system varies greatly between North America and German speaking countries,<sup>44</sup> the differences between Switzerland, Germany and Austria were minimal. Thus, a common experience could be formulated, and these changes were hardly questioned by the end-users during the pilot testing phase.

The two remaining equivalences, namely semantic equivalence and conceptual equivalence were more difficult to separate and, in our experience, were more challenging for the team to reach an agreement. In cross-cultural adaptations of participation measures, specifically the conceptual aspects are often not addressed<sup>14</sup>

and we found it was best to do so through several steps of pilot testing with end-users. We illustrate this issue with the term/concept of “involvement”. A missing suitable word in German (usable equally as a noun and as an adverb) was primarily a semantic issue. However, it became conceptual when parents expressed different understandings of “involvement”. This has been discussed in the participation literature.<sup>5</sup> Involvement implies provided and given access, engagement, and taking part actively rather than conforming to a given social norm.<sup>45</sup> It further includes emotional elements such as motivation, persistence, social connection and level of affect.<sup>5</sup> Proposed by parents, the experts decided to use the German word “Engagement”, which is in line with current scientific discourse.<sup>5,43,46</sup> Involvement also contains aspects of persistence<sup>5</sup> and the German counterpart “Engagement”(G) includes endurance. However, parents of children with disabilities in our study pointed to the fact that the involvement of their children during activities is highly variable. For example, children with ADHD or ASD who have executive functioning limitations, might have difficulties starting activities that they later engage in energetically. Further, as endurance might be weak for some children, parents are confronted with the question of whether they focus their judgement on time or quality. While these examples illustrate conceptual challenges, the investigators decided to assign this to “semantic” equivalence, as this was the starting point of the need for a discussion around cultural equivalence.

The environment sections of the PEM-CY also presented conceptual challenges. After filling in a detailed participation section, the generalization required by the environment questions was not well understood by parents. That is, parents filling in the PEM-CY (German) expected to rate the impact of the environment on each of the activities, rather than taking a more general view and considering the impact on participation in all activities within a particular setting (i.e., home, school or in the community). This problem reflects a theoretically known difficulty in measuring environment within an ICF framework.<sup>47</sup> Whiteneck and Dijkers describe three coding options: (1) environmental factors are coded alone, without relating these codes to activities and participation. Environmental factors are (2) coded for the ICF component of activity and participation generally and (3) environmental factors are coded in combination with capacity and performance qualifiers for each item of activities and participation separately.<sup>47</sup> Participants filling in the environmental section of PEM-CY expected the third version, as they also answered the participation sections (frequency, involvement and wishes for change) for each activity separately. For conceptual clarity,

the statement *“respond to the following as generally as possible”* was added to the PEM-CY (German) in all three environmental sections. As often recommended in cultural adaptation processes, this added example helped to avoid confusion over item meaning.<sup>42</sup>

While the cross-cultural process followed in this study had many strengths, the analysis revealed an interesting pattern. Comparison of original PEM-CY and the two backtranslations (BT1 and BT2) revealed a total of 102 differences in wording or phrasing of the questionnaire. 56% of the differences was caused by English synonyms, 22% of differences were due to English words that cannot be translated in their full meaning into German, thus reflecting aspects of semantic equivalence. 18% of differences occurred due to activity adaptations, reflecting experiential equivalence, the expert team had made in stage II. For only 4% of the differences, the reason could not be determined (e.g., “not an issue” (O) versus “not applicable”). It was not possible to determine the correspondence between the total equivalent changes and the number of differences. However, the changes made following the cognitive interviews with parents were primarily categorized as experiential equivalence, changes that were not identified by the expert team when developing the first pre-final version.

One limitation of this work is that due to the complexity of the PEM-CY, it was not possible to reach the level of comprehension of a twelve year old, as recommended in the guidelines.<sup>28</sup> As a result, parents with lower literacy levels needed help completing the measure. This suggests that the clinicians and researchers may need to modify the self-completed administration of the PEM-CY (German) when it is being used with parents who have reduced German language level or low literacy. This is of particular relevance as the rate of foreign population ranges between 12% in Germany and 22% in Switzerland.<sup>48</sup> An additional limitation is that due to our inclusion criteria, some of the results may not be relevant for parents of children without disabilities. Similar research with parents of children without disability did not find problems in answering the environmental sections.<sup>24</sup> It could be that parents of children with disabilities, who face more environmental barriers compared to parents of children without disabilities,<sup>23,49,50</sup> display more difficulties in answering questions in the environment section. Finally, the selected guidelines<sup>28</sup> did not contain “operational” or “measurement” equivalence, as described in other guidelines<sup>51</sup> and this may limit the generalizability of the findings.

## FURTHER RESEARCH AND PRACTICAL IMPLICATIONS

As with all culturally-adapted measures, the PEM-CY (German) needs to be tested to establish psychometric properties and validated in different research and clinical contexts, and with different groups of children and adolescents.<sup>28,52</sup> It also has to be disseminated and its practical use in the German speaking context examined. In addition, existing measures with the same constructs (e.g. the Young Children's Participation and Environment Measure (YC-PEM)<sup>53</sup> and the PEM+<sup>54</sup>) should be coordinated with this present adaptation to maintain consistency in wording.

Referring to the practicability of the PEM-CY, parents strongly felt it should be completed together with a therapist face-to-face to jointly identify intervention goals and strategies.<sup>55</sup> Filling it in independently, did not provide them with new insights per se, and some parents of children with severe health conditions felt overly disappointed as they were reminded of their child's limitations. If a therapist works with the family while they are completing the PEM-CY, the therapist can coach the family and enable them to see the possibilities for their child.

## CONCLUSIONS

This study presents a cross-cultural translation and adaptation process to develop a German version of the PEM-CY that is suitable for three German speaking countries. As participation and environment are both complex concepts to measure, conceptual equivalence posed the greatest challenges for this cultural adaptation. With extensive input from parents, expert therapists, and researchers, as well as the PEM-CY team from CanChild, a culturally adapted version of PEM-CY (German) is now available for research, practice, and further validation.

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# CHAPTER 5

Parents' perceptions: Participation patterns and desires for change for children and adolescents with autism spectrum disorder – a descriptive population-based study from Switzerland (part 1)



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*Submitted*

# CHAPTER 6

Parents' perceptions: environments and the contextual strategies of parents to support the participation of children and adolescents with autism spectrum disorder - a descriptive population-based study from Switzerland (part 2)



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## ABSTRACT

Environments have a modifying effect on the participation of children and adolescents with autism spectrum disorder (ASD) in all areas of life. This cross-sectional study investigated parental perspectives on supportive or hindering environments and the daily contextual strategies parents used to enhance their children's participation. Qualitative and quantitative data gathered from 115 parents from German-speaking Switzerland using the Participation and Environment Measure – Child and Youth (PEM-CY) were analyzed. Results revealed 45 environmental supports and barriers at home, at school, and in the community. Contextual strategies were identified in combination with people, activities, time, objects, and places.

Parental perspectives on participation and their contextual strategies should be considered in environmental-based interventions to support the participation of children and adolescents with ASD.

## INTRODUCTION

The environment can be a support or a barrier to the participation of children and adolescents with Autism Spectrum Disorder (ASD) in all areas of life and it plays an important role in their development, health, and wellbeing.<sup>1</sup> For example, sensory responsiveness to physical features such as noise or light has been described as a barrier to their participation,<sup>2</sup> while enacted friendships can protect against anxiety and loneliness in children and adolescents with ASD and thus can serve as a supportive environment.<sup>3</sup> The World Health Organization's (WHO) definition of participation as *"involvement in life situations"*<sup>4,5</sup> is extended here to include *"being engaged in and/or performing meaningful activities in occupational and social roles while attending"*.<sup>6(p2)</sup> Activities like after-school sports, shared family activities, or doing homework<sup>7-9</sup> are embedded in an environment, which plays a mediating role in the participation of children with disabilities.<sup>1,10-13</sup> To explore the multi-dimensional construct of the environment, this article differentiates between environment, setting, and context (see figure 6.1), which all encompass external conditions that affect participation: environments most generally, and context most specifically.

Reduced participation of children and adolescents with ASD has been reported in settings such as home, school, or the community. At home, they participate less frequently and are less involved in personal care activities and socializing with other people.<sup>14,15</sup> At school, less frequent socializing activities, fewer friends, and less frequent physical activities are reported.<sup>16,17</sup> In the community, their participation in leisure activities, socializing with peers, attending public events, or using public services is reduced as well.<sup>11,18-20</sup>

Concerning the environment, there is emerging evidence that environments as seen from parents' perspectives are less supportive of the participation of children and adolescents with ASD compared to their peers without disabilities.<sup>18,21,22</sup> Because environment and participation are inherently associated with national socio-economical factors, previous research from Israel<sup>21</sup> and Iceland<sup>18</sup> needs to be supplemented with additional national data.

Qualitative research from Switzerland has explored environmental supports and barriers to the participation of adolescents with ASD and found that adolescents are dependent on environmental pre-requisites to even attend participation.<sup>23</sup> Parent advocate groups in the field of autism aim to implement autistic-friendly environments in malls and cinemas.<sup>24</sup> However, there is an officially recognized paucity of research

describing the living situations of children and adolescents with ASD and their families in generally and specifically with an environmental focus in Switzerland.<sup>25</sup>

Family and specifically parents live in a strong “transactional relationship” with their children and adolescents with ASD. The “transactional relationship” between a person and a context (see definitions Table 6.1) results in changes to both the individual and the environment over time.<sup>26–30</sup> Parents are not only the best-informed people regarding their children and adolescents with ASD but actively create immediate social and physical contexts for their children at home and greatly influence further contexts at school and in the community. The parental role in providing a secure environment and helping to connect children socially has been found to be essential to supporting the participation of adolescents with ASD.<sup>6</sup> This contextual support is provided by parental strategies such as planning, motivating, and guiding. Research describes parental strategies for children with physical disabilities<sup>31</sup> but little is known about parental strategies for children with and without ASD in the home setting<sup>14</sup>, and to our knowledge, there is no information about school and community settings. Further, strategies tailored specifically to children and adolescents within the diverse spectrum of ASD might differ from those of a general population. In adolescents with ASD and anxiety, reported parental strategies to increase community participation included preparing, practicing participation in advance, and avoiding specific triggers or sensory overload.<sup>32</sup>

We need to enhance our understanding of environmental aspects and parental contextual strategies that foster participation at home, at school, and in the community. This is relevant because identified supports or barriers can be more specifically targeted. Therefore, the purpose of this study is to explore the environmental and contextual aspects affecting the participation of children and adolescents with ASD in Switzerland from the parental perspective. More specifically, two questions are formulated:

1. What aspects of the environment at home, at school, and in the community do parents of children and adolescents with ASD living in Switzerland describe as supports and as barriers for the participation of their children?
2. What contextual strategies do parents of children and adolescents with ASD describe using to enhance the participation of their children at home, at school, and in the community in Switzerland?

This article is part of a larger study where we investigate parents' perceptions about participation and the environment regarding children and adolescents with ASD. This present article (part 2) focuses on parental perspectives on the environment and parents' contextual strategies to enhance participation, while the first part (reference) describes the participation patterns of children and adolescents with ASD from the parental perspective, combined with parental desires for change regarding their children's participation.

**Table 6.1** Definitions

Participation	The definition of WHO " <i>involvement in life situations</i> " <sup>4</sup> is extended here to include " <i>being engaged in and/or performing meaningful activities in occupational and social roles while attending</i> ". <sup>6(p2)</sup>
Environment	" <i>The physical, social, and attitudinal environment in which people live and conduct their lives.</i> " <sup>5(p5)</sup> The environment can be a support or a barrier for participation.
Setting	Used in PEM-CY to cluster a group of contexts with similar circumstances and conditions such as "home", "school," and "community."
Context	" <i>Experienced and situated activity settings</i> ". <sup>33(p1835)</sup> Contexts are described with five inherent elements: people, place, activity, objects, and time. Contexts are where transactions take place and their effects can be noticed.

## METHOD

### DESIGN

A population-based cross-sectional descriptive study was selected, describing features at a given point in time. 'Environment,' defined according to the definition of the World Health Organization (see Figure 6.1), can be qualified as barriers or as supports to participation. Supporting environments are those addressing the human desires to explore, understand, enhance competence, be part of the solution, and participate with others towards meaningful goals.<sup>34,35</sup> Parental contextual strategies are those enacted in "experienced and situated activity settings"<sup>33(p1835)</sup> and are described with five inherent elements of contexts: people, place, activity, objects, and time.<sup>33</sup>

### PARTICIPANTS

Participants were German-speaking parents, caring for one or more children between 5 and 17 years with a recognized medical diagnosis of ASD according to ICD-10 (actual diagnostic classification in Switzerland). For the self-selected sample, parents were



recruited through invitation letters sent through multiple different pathways in the German-speaking part of Switzerland. A website provided further information and a link to an online survey. Further recruitment strategies are explained elsewhere (referring to article part 1). Parents provided online informed consent. This survey received a jurisdictional declaration of non-objection by the cantonal ethical committee of Zurich (BASEC Request 2018-00238).

## MEASURES

The online questionnaire consisted of the German version of the Participation and Environment Measure – Child and Youth (PEM-CY(G))<sup>36,37</sup>, demographic questions, and questions about the actual manifestations of ASD symptoms. To describe the sample with regards to the severity of autistic traits and children’s capacities, parents judged actual ASD manifestations according to ICD-10 diagnostic criteria (e.g., communication, restricted and repetitive behavior) and reported challenges described by parents of children with ASD (e.g., ability to express themselves, difficulty handling change, sleeping situation, self-injuring behavior, age-appropriate independence).<sup>38</sup> The eleven manifestations were rated for the last four months on a Likert scale between 1 and 6. The scales were formulated with qualitative anchors (e.g., 6 = “Our child can express himself or herself age appropriately or better” versus 1 = “The expressive language of our child is very low”).

The PEM-CY is a standardized parent-reported assessment of the extent and patterns of participation of children and youth between 5 and 17 years and parents’ desires for change in three different settings (home, school, and community). For each of these three settings, 10 to 17 different environmental aspects, divided into “helpfulness” (e.g., sensory features, demands, socializing persons, attitudes) and “resources” (e.g., services, information, time, or money) are assessed. Parents are asked whether these aspects are helpful or available, which are operationalized in PEM-CY as “supports,” or not helpful, which are operationalized in PEM-CY as “barriers.” Parents are further asked open-ended questions to describe three contextual strategies that they apply to support the participation of their children in each setting. PEM-CY has demonstrated adequate internal consistency and test-retest reliability.<sup>39</sup> It has been applied to young people with ASD.<sup>14,18,21,22,40–42</sup> For this study, we used a German-translated and cross-cultural adapted version of the PEM-CY(G).<sup>37</sup>

After a two-step pilot study (the process is described in more detail in part 1), data collection took place between March and October 2020. Due to the Covid-19 lockdown

and restrictions, parents were asked to refer to participation experiences in the time before the lockdown for their answers.

## ANALYSIS

The quantitative data were analyzed using IBM SPSS Statistics (Version 27.1) analytical software.

### *Demographics*

Demographics of parents and youth were summarized and total numbers, percentages, and means and/or medians were calculated for the whole sample and two age groups (5-11 years and 12-17 years). Based on the data level, *t*-tests or Mann-Whitney *U* tests were performed to indicate a statistically significant difference level of  $p=0.5$  for demographic data. Parent-reported manifestation of ASD was calculated using the median and quartile range for the whole group and the two sub-groups. Calculations were based on Tukey's range tests to account for the ordinal scale used.

### *Analysis of environmental "supports" and "barriers"*

PEM-CY measures 45 total environmental aspects. Their number varies per setting (home: 12; school: 17; community: 16). As recommended by the PEM-CY user guide, environmental aspects judged with *"usually helps"* and *"usually yes"* were viewed as "supports" and those judged with *"usually makes harder"* or *"usually no"* were viewed as "barriers." We calculated the average amount of perceived "support" and "barriers" for all three settings, both age groups, and the whole sample. For more in-depth insight, we calculated for each of the 45 environmental aspects the percentage of parents who opted for a particular answer in each age group and in the whole sample.

### *Analysis of parental contextual strategies to support participation*

For each setting (home, school, and community), parents were asked in an open-ended question (part of the PEM-CY) to list three strategies that they use to support their children's participation. We received very rich data. We decided on a secondary analysis by posing another research question beyond those originally intended with the primary data.<sup>43</sup> The same two researchers (BK, TM) applied a summative content analysis, typically used to explore word usage or contents in texts.<sup>44</sup> It is seen as a deductive approach.<sup>45</sup> The two native German-speaking researchers used the five

aspects of context (people, place, activity, objects, and time) as defined by King et al.<sup>33</sup> as pre-determined codes. After agreeing on definitions in a codebook, both coded the written comments of parents, which were separated for the three settings (home, school, and community) and were divided into two age groups (children and adolescents). Next, they compared, discussed, and reflected on their results. They also looked for comments that could not be coded with these codes. Then, they presented the qualitative results to a third native-speaking researcher (AM) to refine it further. After translating the results and exemplary codes into English, they presented the results to the whole team, and calculations, contents of the table, and a narrative summary report were agreed on.

## RESULTS

Results are divided into three parts: (1) the description of the study sample; (2) the presentation of parents' perceptions of environmental aspects as "supports" and "barriers" in 45 environmental aspects along the three settings differentiated between the two age groups; (3) and a summary of the analysis of 623 received comments about the contextual strategies of parents according to the five aspects of context: people, place, activity, objects, and time.

### DESCRIPTION OF THE STUDY SAMPLE

The final analysis included 115 participants. The flow of eligibility can be found in article 1 (reference). The demographics of the 115 parents are listed in Table 6.2. Overall, 60 parents reported on children (5-11 years of age) while 55 reported on adolescents (12-17 years of age). Statistically, the two groups did not differ significantly ( $p=0.5$ ) with regards to responding parents, community type of residence, and education level of parents. However, the family constellation differed statistically in adolescents, who lived more often in separated households. Further, the paid working hours of mothers of adolescents with ASD were higher than those of mothers of children with ASD.

The demographics of the children and adolescents with ASD are listed in Table 6.3. The two age groups differed statistically in the average age of diagnosis, number diagnosed with Asperger's syndrome, and the number of friends and peers (meetings via social

media) they meet with per week. 15-20% of parental answers for informal friendships and social media contacts were missing.

**Table 6.2** Demographic characteristics of parents answering questions for their children or adolescents with ASD.

	Children with ASD		Adolescents with ASD		Total group of youth	
	Age 5-11, N=60		Age 12-17, N=55		Age 5-17, N=115	
	n	%	n	%	n	%
<b>Responding Persons</b>						
Mother <sup>1</sup>	46	78.0	49	89.1	95	83.3
Father <sup>1</sup>	9	15.3	4	7.3	13	11.4
Both together <sup>1</sup>	4	6.8	2	3.6	6	5.3
<b>Community type of living</b>						
Urban <sup>1</sup>	9	15.0	5	9.1	14	12.2
Rural <sup>1</sup>	38	63.3	28	50.9	66	57.4
Agglomeration (suburbs)	13	21.7	22	40.0	35	30.4
<b>Family constellation</b>						
Child lives with both parents together	52	86.7	41	74.5	93	80.9
Parents separated; child lives in two households	0	0.0	4	7.3	4	3.5
Parents separated; child lives overly with one parent <sup>1</sup>	5	8.3	6	10.9	11	9.6
Child lives with one parent in a new family <sup>1</sup>	2	3.3	2	3.6	4	3.5
Other or missing <sup>1</sup>	1	1.7	2	3.6	3	2.6
<b>Number of siblings of child with ASD</b>						
No siblings	22	36.7	13	24.1	35	30.7
One sibling <sup>1</sup>	24	40.0	26	48.1	50	43.9
Two or more siblings <sup>1</sup>	14	23.3	15	21.7	29	25.5
<b>Education of mother</b>						
Obligatory <sup>1</sup>	3	5.0	2	2.6	5	4.3
Secondary education <sup>1</sup>	17	28.4	18	32.7	35	30.4
Tertiary education <sup>1</sup>	40	66.7	33	63.6	75	65.3
Unknown or missing <sup>1</sup>	0	0.0	0	0.0	0	0.0
<b>Education of father</b>						
Obligatory <sup>1</sup>	1	1.7	1	1.8	2	1.7
Secondary education <sup>1</sup>	15	25.0	11	20.0	26	22.6
Tertiary education <sup>1</sup>	42	70.0	39	71.0	81	70.4
Unknown or missing	2	3.3	4	7.2	6	5.3
<b>Further information of the family</b>						
Actual percentage of paid work of mother	33.1*	31.32**	49.9*	33.25**	41.1*	33.20**
Actual percentage of paid work of father	87.1*	27.31**	80.5*	33.76**	84.0*	30.57**
Number of languages spoken in the inner family	1.42*	0.72**	1.53*	1.42**	1.47*	1.1**

\*mean \*\*SD 1no significant difference at the  $p=0.5$  level.

The distribution of autistic symptoms in the children and adolescents with ASD was determined from the statements of the parents (manifestation of ASD symptoms). *“Expressive language ability,” “use of communication aids,” “intellectual abilities,”* and *“no self-harming behavior”* were rated highly in both groups, indicating a less severely affected autistic sample. *“Reaction to change,” “repetitive behavior,” “restricted behavior,”* and *“selective eating pattern,”* were rated in the middle range for both sub-groups. In contrast, *“sleeping situation,” “interaction with other children,”* and *“age-appropriate independence”* scored in the middle range, though there was more variation in adolescents with ASD than in children with ASD. Solely *“reaction to change”* presented with a high spread in both groups.

**Table 6.3** Demographic characteristics of children and adolescents as described by parents.

	Children with ASD		Adolescents with ASD		Total group of youth	
	Age 5-11y; N = 60		Age 12-17y; N = 55		Age 5-17y; N = 115	
	n	%	n	%	n	%
<b>Gender</b>						
Male <sup>1</sup>	51	85.0	41	74.5	92	80.0
Female <sup>1</sup>	9	15.0	14	25.5	23	20.0
<b>Type of ASD</b>						
Autism Spectrum Disorder <sup>1</sup>	16	26.7	11	20.0	27	23.5
Early onset autism <sup>1</sup>	10	16.7	8	14.5	18	15.7
Asperger Syndrome	23	38.3	33	60.0	56	48.7
Atypical autism <sup>1</sup>	5	8.3	3	5.5	8	7.0
Other not specified	6	10.0	0	0.0	6	5.2
Age of Diagnosis	5.6*	2.12**	8.5*	3.41**	7.0*	3.15**
<b>Main Co-morbidity</b>						
No co-morbidity	34	56.7	19	34.5	53	46.1
ADHD <sup>1</sup>	11	18.3	12	21.8	23	20.0
Anxiety <sup>1</sup>	1	1.7	4	7.3	5	4.3
Epilepsy <sup>1</sup>	0	0.0	1	1.8	1	0.9
Depression <sup>1</sup>	1	1.7	4	7.3	5	4.3
Motor dysfunction <sup>1</sup>	4	6.7	2	3.6	6	5.2
Others or unknown	6	10.0	11	20.0	14	14.8
<b>Schooling</b>						
Regular setting without adjustments <sup>1</sup>	8	13.6	8	14.8	16	14.2
Regular setting (minor adjustments) <sup>1</sup>	20	33.9	13	24.1	33	29.9
Regular setting (special adjustments) <sup>1</sup>	9	15.3	6	11.1	15	13.3
Private school <sup>1</sup>	7	11.9	13	24.1	20	17.7
General separate school <sup>1</sup>	13	22.0	8	14.8	21	18.6
Home or boarding school <sup>1</sup>	1	1.7	2	3.8	3	2.7
Vocational apprenticeship	0	0.0	3	5.6	3	2.7
None or missing <sup>1</sup>	1	1.7	3	5.6	4	3.6
<b>Friendships (outside school)</b>						
Personal friends meeting per week	1.4*	2.04**	0.7*	0.94**	1.1	1.64**
Informal peers meeting per week <sup>1</sup>	2.74*	4.64**	3.0	4.22**	2.8	4.41**
Peers meeting via social media per week	0.6*	1.81**	3.1	4.33**	1.8	3.55**

\*mean \*\*SD <sup>1</sup>no significant difference at the  $p=0.5$  level.

## PARENTS' PERCEPTIONS OF ENVIRONMENTAL ASPECTS IN THREE SETTINGS

Table 6.4 lists the percentages of parents' perceived judgements of the 45 environmental aspects in three settings. Half of all parents indicated clear environmental "supports" and "barriers" to the participation of their children. From this half, both age groups were perceived to have more "supports" than "barriers" in all three settings. The average number of perceived supports in the three settings (home:  $M=4.6$ ,  $SD=2.3$ ; school:  $M=6.2$ ,  $SD=3.4$ ; community  $M=5.4$ ,  $SD=2.7$ ) was over 50% higher than the average number of perceived "barriers" (home:  $M=1.1$ ,  $SD=1.3$ ; school:  $M=2.8$ ,  $SD=3.0$ ; community  $M=3.0$ ,  $SD=3.0$ ). There were only minor differences between the age groups.

The other half of parents did not indicate environmental "supports" or "barriers" clearly. Out of these, two groups could be distinguished: first, a third of all parents choose *"sometimes yes/helpful, sometimes no/hard"* (home: 31%; school: 27%; community: 30%), indicating a swing between the environment being a "support" or being a "barrier." Second, for 20% of all parents, environmental aspects were *"not an issue"* (home: 21%; school: 17%; community: 17%). Most of the 115 parents answered all 45 questions. "Attitudes" had the lowest answer rate with 108, as seen in Table 6.4. In the following paragraph, the highest percentages of "supports" and "barriers" are reported along each of the three settings. At home, parents judged most of the environmental aspects as "supports." Specifically, "resources" (such as "supplies," "information," "money") were rated highly. "Sensory quality" and "social demands of activities" were perceived as strong "barriers" in the home setting. At school, "attitudes" of teachers and staff and most of the "resources" (such as "programs and services," "information," and "time") were rated as strong "supports." Highly endorsed "barriers" at school were the "sensory quality" and the "social demands of activities." In the community, parents judged that only "safety" was a clear support regarding aspects of "helpfulness," while most "resources" (such as "transportation," "policies and procedures," "information," "time," and "money") were also rated as strong "supports." Clear "barriers" in the community were "sensory quality" and the "social demand of activities." The community was the setting in which most parents chose to swing between *"sometimes helps and sometimes makes harder."*

**Table 6.4** List of 45 environmental aspects in three settings: percentages of parents.

	SUPPORTS												BARRIERS					
	"Do the following things help or make it harder to participate in activities at home?"												"Sometimes helps, sometimes makes harder"			"Usually makes harder"		
	"Not an issue"			"Usually helps"			"Sometimes helps, sometimes makes harder"			"Usually makes harder"								
	N	all	<11	>11	all	<11	>11	all	<11	>11	all	<11	>11	all	<11	>11		
HOME ENVIRONMENT	1. Physical layout	113	35	13	21	24	14	10	36	21	15	5	3	3				
	2. Sensory quality	113	19	10	10	15	7	8	42*	20	22	23	14	9				
	3. Physical demands of activity	114	35	16	13	16	8	8	39	21	18	16	7	9				
	4. Cognitive demands of activity	113	27	12	15	21	12	9	37	21	16	15	6	9				
	5. Social demands of activity	113	16	7	9	27	14	12	40	23	17	18	7	11				
	6. Relations with family members	114	16	8	8	32	18	15	46	25	22	5	2	4				
	7. Attitudes	106	33	16	17	28	17	11	39	10	19	9	7	3				
"Are the following available and/or adequate to support your child's participation at home?"																		
	"Not needed"			"Usually yes"			"Sometimes yes, sometimes no"			"Usually not"								
	N	all	<11	>11	all	<11	>11	all	<11	>11	all	<11	>11	all	<11	>11		
Resources	8. Services	115	76	37	39	10	7	3	7	4	3	8	4	3				
	9. Supplies	115				90	47	43	10	5	4	8	4	3				
	10. Information	115				76	41	37	20	10	10	2	1	1				
	11. Time	115				52	25	26	47	27	20	2	0	2				
	12. Money	115				65	33	35	23	16	8	9	3	5				
"Do the following things help or make it harder to participate in activities at school?"																		
	"Not an issue"			"Usually helps"			"Sometimes helps, sometimes makes harder"			"Usually makes harder"								
	N	all	<11	>11	all	<11	>11	all	<11	>11	all	<11	>11	all	<11	>11		
SCHOOL ENVIRONMENT	1. Physical layout	111	21	8	13	27	15	12	36	17	19	16	10	6				
	2. Sensory quality	111	4	0	4	14	7	7	29	17	12	53	26	27				
	3. Weather conditions	111	42	18	24	8	5	4	34	14	20	15	14	2				
	4. Physical demands of activity	111	16	4	13	14	8	5	37	20	17	33	19	14				
	5. Cognitive demands of activity	110	13	4	9	20	11	9	35	19	15	33	16	16				
	6. Social demands of activity	110	6	3	4	12	6	5	44	21	23	50	20	18				
	7. Attitudes	108	5	1	4	44	28	17	40	17	23	11	6	6				
	8. Relations with peers	110	10	5	5	22	14	8	48	23	25	20	8	12				
	9. Safety	109	22	8	14	37	18	18	24	16	8	17	7	10				

SCHOOL ENVIRONMENT																											
"Are the following available and/or adequate to support your child's participation at school?"																											
Resources		N	all	<11	>11	all	<11	>11	all	<11	>11	"Sometimes yes, sometimes no"				"Usually yes"				"Sometimes helps, sometimes makes harder"				"Usually makes harder"			
10. Personal transportation		112	63	32	30	34	18	16	4	1	3	0	0	0													
11. Public transportation		112	60	37	23	37	13	24	1	0	1	3	1	2													
12. Programs and services		112	14	6	8	49	26	23	19	8	11	18	11	7													
13. Policies and procedures		111	22	9	13	43	20	23	20	10	10	15	12	4													
14. Supplies		112				77	38	39	19	12	7	4	2	3													
15. Information		111				63	32	32	30	15	14	7	4	4													
16. Time		113				67	35	32	31	16	15	2	0	2													
17. Money		112				75	35	40	19	12	7	6	4	2													
"Do the following things help or make it harder to participate in activities at school?"																											
Helpfulness		N	all	<11	>11	all	<11	>11	all	<11	>11	"Sometimes helps, sometimes makes harder"				"Usually helps"				"Sometimes helps, sometimes makes harder"				"Usually makes harder"			
1. Physical layout		114	47	20	27	16	11	5	27	15	12	10	6	4													
2. Sensory quality		114	9	2	7	8	4	4	39	20	18	45	26	20													
3. Physical demands of activity		113	24	8	16	9	2	7	35	24	11	33	19	14													
4. Cognitive demands of activity		114	30	9	21	7	4	4	29	18	11	34	21	13													
5 Social demands of activity		113	11	4	7	9	5	4	40	23	17	40	20	20													
6. Relations with peers		113	15	3	9	13	7	6	42	24	18	31	15	16													
7. Attitudes		113	7	3	4	19	11	9	48	25	23	26	13	13													
8. Weather conditions		114	45	19	25	4	2	2	40	21	19	11	10	2													
9. Safety		114	18	9	9	32	16	17	28	17	11	22	11	10													
"Are the following available and/or adequate to support your child's participation in the community?"																											
Resources		N	all	<11	>11	all	<11	>11	all	<11	>11	"Sometimes yes, sometimes no"				"Usually yes"				"Sometimes helps, sometimes makes harder"				"Usually not"			
10. Personal transportation		115	17	8	10	76	39	37	5	4	1	2	1	1													
11. Public transportation		115	29	18	10	68	31	37	3	3	0	1	0	1													
12. Programs and services		115	30	16	14	37	17	20	18	9	10	15	10	5													
13. Information		112				55	25	30	31	18	13	13	8	5													
14. Equipment and supplies		112				65	30	35	28	18	10	7	3	4													
15. Time		111				57	31	26	29	20	18	4	1	3													
16. Money		113				70	34	36	22	13	9	8	4	4													

\*bolded if more than 40% of all parents opted for this.



A summary of “supports” and “barriers” is presented for each setting graphically in Figure 6.1. It is apparent (as reported earlier) that in all three settings, parents reported more “supports” than “barriers,” with a decline in support from home to school to the community. Next, the distribution regarding the 45 environmental aspects remained nearly similar for both age groups. Differences over 10% between age groups were found in “*weather conditions*,” which were stronger “barriers” at home in younger ages. Supportive “*attitudes*” at school were higher in children with ASD than in adolescents with ASD, while the reverse was true for “*public transport*” at school.

**Figure 6.1** Percentages of supports and barriers in two age groups as perceived by parents.



Not all “supports” and “barriers” per setting were equally distributed. Parents in all three settings perceived more “supports” in aspects summarized as “resources” (such as “services,” “information,” “time,” “money”) than those summarized under “helpfulness” (such as “physical layout,” “sensory qualities,” “physical demands,” “social demands,” “attitudes,” or “social relations”). This is mirrored by “barriers” in all settings: parents perceived more “barriers” in aspects summarized under “helpfulness” than those summarized as “resources.”

## CONTEXTUAL STRATEGIES OF PARENTS TO SUPPORT PARTICIPATION

We present a summary of contextual strategies using the five themes of “people,” “activity,” “time,” “objects,” and “place,” which are presented in nine clusters such as “encouraging participation” or “accompanying, sharing, or supervising activities.” Each cluster contains several single strategies. Table 6.5 lists five themes and nine clusters and describes 22 single strategies, for which exemplary quotes from three settings and two age groups are displayed. Most strategies were used in all three settings. In total, 624 strategies were mentioned (home: 231 strategies; school: 220 strategies; community 172 strategies). We found only minor differences between the age groups. The most mentioned contextual strategies are presented first.

### *“People”: parents use their relationships to support participation*

We clustered 41% ( $n=257$  strategies) of all data in three clusters under “people.” In the first cluster, called *encouraging participation*, parents used their empathic relationships with their children to motivate them, appraise their efforts, and encourage involvement. Being observant and sensitive to their children’s needs allowed parents to react immediately and adapt their appraisal and their strategies. In the second cluster of strategies, parents *accompanied their children’s participation* in various ways. Accompanying transitions to school was often mentioned. Shared participation in the community was described as securing and affirming for children and adolescents with ASD. In the home setting, parents described the meaningfulness of shared family activities and how they naturally expected participation and involved their children with ASD in these activities. Performing school activities together with their children at home was another accompanying strategy. Parents supported their children’s learning and prepared them to cope with school demands. Finally, in the home setting, parents supervised their children’s participation or organized other persons to supervise them.

In the third cluster of strategies, parents *enhanced the social relationships* of their children as well as their own; they actively worked to maintain a positive relationship with school personnel to influence school activities and become informed about their children's issues at school (15% of all strategies at school). To enable a positive participation experience, parents reframed (such as explained and briefed) the social environments regarding the needs and behavior of their children. This enhanced understanding, empathy, and positive attitudes for their children with ASD. Involving wider family, friends, children, and peers was mentioned more often in home and community settings. Only 8 comments mentioned involving other peers actively.

*“Activities”: parents influence participation through activities*

We gathered 35% ( $n=219$ ) of all comments in three clusters under “activities”.

The first cluster of strategies was based on parents' intensive search for suitable activities for their children. When choosing these activities, they considered their children's interests, conveyed joy and fun to them, and motivated them by providing choices or asking them for help. Specifically for community participation, parents reported difficulties finding optimal settings and activities for their children with ASD.

In the second cluster of strategies, parents *planned and organized these activities* in detail to be able to accurately prepare their children with ASD for later activities. 15% of all comments referred to preparing children and adolescents with ASD beforehand. Parents mentioned how they repeatedly provided goal-oriented information about future activities. To ensure a sense of security, parents reported delivering the information in a precise and instructive manner.

In the third cluster under “activities,” parents started, modelled, graded, and adapted the demands of activities, so their children with ASD could join and have a positive participation experience (as the ultimate goal).

The next three parental strategies are clustered in one cluster with similar strategies.

*“Time”: parents use aspects of time to support participation*

Applying strategies connected to “time” (11% of all comments), parents opted for regularity and rituals (often also in combination with rules), provided altogether more time for participation experiences, and reduced the pace of activities. Parents mentioned they reduced the total length of activities or planned free time slots between activities. Parents described further how they were mindful of the actual state of mind of their child. Waiting for the “right” moment to introduce a new activity or being well-rested before a socially-demanding participation experience seemed central.

**Table 6.5** Parental strategies to support participation.

Clusters of strategies		Single strategies	Explanation of parental contextual strategies	Three Settings		Children (age 5-11 years) exemplary quotes from home (H), school (S), and community(C)	Adolescents (age 12-17 years) exemplary quotes from home (H), school (S), and community(C)
				(H)	(S)	(C)	
Theme: "PEOPLE": parents use their relationship to support participation (257 comments; 130 children; 127 adolescents)							
Encouraging participation (62 comments)	Confirming and motivating (46 comments)	Parents try to motivate. They give positive feedback and encourage involvement.	x	x	x	"Confirm what we do together with a lot of pride and praise" (H) "We praise him" (S) "We try a lot and encourage him" (C)	"Motivation plan" (H) "Encouragement" (S) "Give him tips and motivate him" (C)
Accompanying, sharing, and supervising activities (118 comments)	Applying a needs and age-oriented attitude (16 comments)	Parents are sensitive to children's needs and treat them age-appropriately.	x	x	x	"Listen carefully to the child: sometimes something works and sometimes it doesn't. But we often don't know why either" (H) "Adjustments according to his needs" (C)	"Make sure that information that might be of interest arrives and is read" (H) "I always remind him of his career aspirations so that he can find the strength and motivation for school" (S)
Performing school activities at home (32 comments)	Accompanying child's participation (41 comments)	Parents accompany their children on the way to school, at school, and while they participate in the community.	x	x	x	"We accompany him to school, otherwise it wouldn't work" (S) "If there is no teaching staff, I help out or the child stays at home" (S) "Mother always comes with him" (C)	"Sometimes bring her to school to relieve the stress of transferring in the morning so that she can bring all her energy to school" (S) "We support him by providing transport to the places, stay with him there and bring him home again" (C) "Prepare for activities he will do at school (e.g. skiing or giving a lecture)" (S)
Shared family activities (23 comments)	Supervising (22 comments)	Parents expect their children to participate in family activities. Parents organize care or supervision for their children.	x	x	x	"I stopped working ... to be able to support him doing his homework better" (H) "We repeat the school lessons at home so that he progresses at school" (S) "Intensive support with homework" (S) "Joint activities of the family" (H) "Just take the child with you and include it, just like another child" (C)	"Nothing, he just goes along with it" (H) "Count on his participation" (C)
Supervising (22 comments)	Parents expect their children to participate in family activities. Parents organize care or supervision for their children.	Parents expect their children to participate in family activities. Parents organize care or supervision for their children.	x	x	x	"Always make sure that someone is present" (H) "We applied for 100% teaching assistance" (S) "I stopped working ... to be able to support him doing his homework better" (H)	"Check e.g. that he doesn't run from the bathroom to his computer" (H) "Involve external professionals, from school we do not expect a lot" (S)

Table 6.5 (continued)

Clusters of strategies		Explanation of parental contextual strategies		Three Settings (H) (S) (C)		Children (age 5-11 years) exemplary quotes from home (H), school (S), and community(C)	Adolescents (age 12-17 years) exemplary quotes from home (H), school (S), and community(C)
Enhancing social relations and bridging (56 comments)	Building relationships with school personnel (30 comments)	Parents keep regular positive contact with teachers or other personnel at school to be informed and influence decisions.		x		"Close collaboration with kindergarten teacher"(S) "Many talks with head of school and teachers, initiated through us" (S)	"Good contact with special needs teacher and main teacher" (S) "Regularly contact with school so we can support their decisions"(S)
	Reframing (26 comments)	Parents explain to the social environment (such as siblings, teachers, organizers, or parents of other children) the needs or behavior of their children.	x	x	x	"We try to explain it to the little sister and thus bridge the gap between the two age groups" (H) "We speak openly with her teachers, explain her anxieties and try to find solutions together" (S) "To inform organizers and trainers in advance about possible complications or premature termination" (C) "Using his sister as a motivator" (H) "We maintain good relationships with parents of peers" (S) "Invite a friend with kids or family member to participate with us" (C)	"We are engaging in the relationship with parents of children our daughter is friends with" (H) "High transparency about diagnosis and problems with teachers" (S) "We try to inform children and parents about autism to increase their comprehension" (C)
	Inviting wider family and friends to participate (10 comments)	Parents maintain contact with wider family, friends, and parents of peers and invite them to participate with their children or visit them.	x	x	x		"Family cohesion" (C)
	Bringing in peers or other children (8 comments)	Parents invite or include peers or other children to support the participation of their child.	x	x	x	"Invite the best friend of our daughter to come along" (H) "Bringing in his best friend who is a class above him" (S) "Emphasize that school friends are also there" (C)	"Laying a good foundation with peers from an early age (offering opportunities to play, cultivating relationships) so that the child experiences himself as an equal member and is more self-confident" (S) "Organizing with his friend play dates to make them more smooth" (C)

Table 6.5 (continued)

Clusters of strategies	Single strategies	Explanation of parental contextual strategies	Three Settings (H) (S) (C)	Children (age 5-11 years) exemplary quotes from home (H), school (S), and community(C)	Adolescents (age 12-17 years) exemplary quotes from home (H), school (S), and community(C)
Theme: "ACTIVITIES": parents influence participation through activities (219 comments; 104 children; 115 adolescents)					
Searching for and choosing interesting activities (58 comments)	Meeting interests of the child and conveying joy and fun (41 comments)	Parents address the interest of their children or make them attractive by conveying joy and fun. They also support implementing interests for participation.	x	x	x
	Giving them choices and asking for help (17 comments)	Parents offer choices or ask for help from their children to let them decide actively for their participation.	x	x	x
Planning and organizing activities and preparing the children and adolescents with ASD (127 comments)	Preparing children in detail beforehand (90 comments)	Parents prepare their children by informing them in advance (goal-oriented/repeatedly) and in great detail (precisely/instructively) about future participation. Additionally, parents of adolescents discuss a lot.	x	x	x
	Planning and organizing (37 comments)	Parents plan activities beforehand and organize to benefit their children's participation.	x	x	x
Performing adapted activities (34 comments)	Starting, modelling, and grading (34 comments)	Parents start an activity and model for their children. They also grade the demands of activities.	x	x	x

Table 6.5 (continued)

Clusters of strategies	Single strategies	Explanation of parental contextual strategies	Three Settings (H) (S) (C)	Children (age 5-11 years) exemplary quotes from home (H), school (S), and community(C)	Adolescents (age 12-17 years) exemplary quotes from home (H), school (S), and community(C)
Theme: "TIME" parents use aspects of time to support participation (70 comments: 34 children; 36 adolescents)					
Opting for regularity, more time and the right moment (70 comments)	Regularity and rituals (30 comments)	Parents stick to regularity and rituals to make daily tasks for their children more predictable.	x	x	"Clear, non-negotiable minimum rules (getting up in the morning, showering, dinner together, handing over your mobile phone)" (H) "Regularly repeated events" (C)
	Creating and adapting time (25 comments)	Parents know that their children sometimes need more time and breaks in-between activities. Thus they use more time to reduce stress.	x	x	"Reduce the pace" (H) "Allowing time and avoiding pressure is usually successful, but it is difficult to get the child to school on time" (S) "...leave between every activity 1-2 hours unplanned time" (C)
	Adapt to the state of mind at the moment (15 comments)	Parents are mindful about the right moment to address new topics or changes.	x	x	"Wait for the right time" (H) "Align with his state of mind in the moment" (C)
Theme: "OBJECTS": parents use objects to communicate and motivate (40 comments: children 17; adolescents 23)					
Providing visual communication and rewards (40 comments)	Visualizing (19 comments)	Parents communicate with graphical or visual methods.	x	x	"Partly detailed process plans that enable independent action" (H) "Prepare with maps or material from the internet" (S)
	Offering rewards (21 comments)	Parents offer rewards and incentives to acknowledge efforts and to motivate them to participate in unpleasant activities.	x	x	"Offer of favorite food or favorite TV show" (H) "Incentives" (S) "Horse trading" with rewards, e.g. media time" (C)

Table 6.5 (continued)

Clusters of strategies	Single strategies	Explanation of parental contextual strategies	Three Settings (H) (S) (C)	Children (age 5-11 years) exemplary quotes from home (H), school (S), and community(C)	Adolescents (age 12-17 years) exemplary quotes from home (H), school (S), and community(C)
Theme: "PLACE": parents chose places with just the right amount of stimuli					
Choosing rooms to avoid or react to sensory overload (38 comments)	Organize possibilities for withdrawal and rest (20 comments)	Provide opportunities for withdrawal or rest to avoid sensory overload.	x	x	"Adjust the furniture (hammock for reading, works very well)" (H) "We stop the activities early to avoid overload" (C)
				"Provide relaxation and opportunities for withdrawal at home, to allow his adaptation capacity, which is overstretched through school, to be balanced again." (S) "Codeword "cal" or "home" when it gets too much" (C) "Learn strategies to cope with sensory overload" (H) "Organize edge seating, window seat" (C)	"Avoid bad-smelling situations" (H) "Familiar surroundings are important. We only go shopping at certain supermarkets, as there are fewer attractions there than at others. According to our son, these discount stores are structured logically and are clearer" (C)



*“Objects”: parents use objects to communicate and motivate*

Parental strategies around “objects” (6% of all comments) were connected to the availability of materials to visualize concepts as this was described as easing communication. “Objects” were also mentioned in combination with rewards and incentives used to motivate the children and adolescents with ASD for externally demanded activities that were often necessary but unpleasant, such as showering or joining a social event.

*“Places”: parents choose places with just the right amount of stimuli*

Last, parental strategies around “places” (6% of all comments) described themes connected to sensory overload. Parents chose rooms or spaces to prevent sensory overload or taught their children strategies to prevent it. Next, parents applied strategies to react to possible sensory overload by looking for places to withdraw or by providing opportunities to rest and restore from sensory overload.

## DISCUSSION

The purpose of this study was to explore parental perspectives on the environmental supports and barriers to the participation of children and adolescents with ASD in Switzerland, as well as related contextual strategies.

Answers to the first set of questions showed that one half of parents perceived more “supports” than “barriers” in all three settings. “Supports” and “barriers” were qualitatively different, but “*sensory aspects*” and “*social demands of activities*” were rated as the highest “barriers” in all three settings. The remaining half of parents swung between more supports and more barriers and thus did not perceive a general “barrier” or “support” in the environment.

Results for the second set of questions showed that contextual strategies were overly connected to “people” (41%) (and thus were social in nature) and “activities” (36%) (representing activity changes to support participation). Most parental strategies were reported similarly in all settings and in both age groups, indicating that environments may stay the same during childhood and adolescence.

## DIFFERENCES BETWEEN SUPPORTS AND BARRIERS

We presented “supports” and “barriers” descriptively and graphically without summary scores. This in contrast to other studies, which used summary scores of supportiveness<sup>46,47</sup> or combined the answers “not an issue” and “usually helps”<sup>14</sup>. Without summary scores it became obvious that in our study “supports” were twice as numerous as “barriers,” and were at the same time different in nature. “Supports” (such as “services,” “information,” “time,” “money,” “equipment and supplies,” and “transportation”) are either automatically provided by the Swiss social system or families in Switzerland can opt for them. Families can opt, for example, to reduce parental workload and thus gain additional time to support the participation of the child or adolescent with ASD.

This freedom of choice contrasts with the perceived “barriers” (such as “sensory quality” “cognitive demands of activities,” “social demands of activities,” “relationships,” and “attitudes”) which are part of the built or socially-constructed environment and go beyond the scope of single families. By scoring these things as “barriers,” parents expressed a certain helplessness. Their ability as parents or families to influence things like environmental noise, social rules, or attitudes to accommodate the needs of their children with ASD is perceived as rather low.<sup>48,49</sup>

Half of the parents swung between reporting the environment as a clear “support” or “barrier,” but instead said the environment served “sometimes as a help and sometimes as a hindrance” or was “not an issue.” Eglison et al.<sup>14</sup> reported a similar pattern. We see two possible explanations for this uncertainty: first, parents found it hard to determine an overall influence of the environment, as demanded by the construct underlying PEM-CY.<sup>23</sup> A dichotomous answer option might not be adequate to capture the complexities of environmental influence. Second, environmental aspects are dependent on enacted contextual situations as proposed by King and co-authors.<sup>33</sup> For example, whether “being together with other people” is supporting or hindering in a setting depends on the persons in the setting. In a school setting, a librarian might be supportive of a child with ASD, while in the same setting, a sports teacher may not be. This swing was primarily found in the community setting. We suspect this is because community or public environments are more diverse and less predictable.

## SUPPORTS AND BARRIERS IN SPECIFIC SETTINGS

“Supports” and “barriers” did not differ considerably across the three settings in our sample, a finding similar to that seen in children and adolescents with non-ASD disabilities.<sup>39,47,50</sup> However, we want to point to two setting-specific particularities:

In a home setting, parents have the operating agency to adapt the environment to the needs of their children and adolescents with ASD. Parents rated *“the relationships with family members”* as the strongest “support” in the home. Family relationships were found to be highly important in other research as well.<sup>6,8,51</sup> Parents rated *“sensory quality”* as the highest “barrier,” indicating a need to find suitable solutions.<sup>15,52</sup> An intervention framework to address sensory issues in the home exists to guide service providers and health workers.<sup>53</sup> It proposes universal design principles and self-regulation strategies to optimize participation experiences for children and adolescents with ASD.

In community settings, the reported barriers from Switzerland exceed those reported from Australia.<sup>22</sup> Differences were specifically found in *“relationships with peers”* (CH 31%; AU 8%), *“safety”* (CH 22%; AU 8%), *“sensory quality”* (CH 45%; AU 33%), and *“social demands”* (CH 40%; AU 35%). Our Swiss sample also reported a higher non-participation rate than the sample from Australia (see reference study 1). The age difference between these two samples (CH: 5-17 years; AU: 5-12 years) could be one explanation for the discrepancy. However, we assume that attitudinal, cultural, or policy differences between the two countries contribute the most to these differences. Unfortunately, most research into attitudes and stigmatization in ASD is nationally-based.<sup>54</sup> From an anthropological viewpoint, research suggests that cultural differences can even mediate environmental differences such as maternal education, ethnicity, and the perceived negative impact of ASD.<sup>55</sup> Region-based cultural aspects need to be included in any further research focusing on transnational environments. Further, a supportive environment should be perceived as supportive from the persons with ASD themselves.<sup>56</sup>

## CONTEXTUAL PARENTAL STRATEGIES A COMBINATION OF “PEOPLE” AND “ACTIVITIES”

The most common contextual strategies of parents (“people” and “activities”) correspond to the two main diagnostic features of ASD:<sup>57</sup> (1) social-communicative differences, connected to strategies we condensed into “people” and (2) restricted and repetitive behavior, connected to strategies we condensed into “activities”. As such,

parents provide support targeted to address autistic traits that hinder the participation of their children with ASD. Further, our results generally reflect the seven strategic patterns Egilson et al.<sup>14</sup> found in adolescents with and without ASD, but we have tailored them more specifically to children and adolescents on the autistic spectrum. In the contextual strategies labeled “people,” parents use their confidential relationship with their children and adolescents with ASD to motivate, provide company, and serve as gatekeepers for new social contacts and participation. Parents and families are the most critical environment in childhood.<sup>58</sup> While less dependence on parents is assumed in adolescence,<sup>29</sup> parents are still extensively involved in the lives of adolescents with ASD. The constant work of securing and helping to form connections,<sup>6</sup> which can involve the parent taking on many different roles—such as motivator, door-opener, or companionship—to create a supportive environment for children and adolescents with ASD, can be tiring over time. Other persons from the wider support circle—friends, practitioners, or service providers—can relieve some of the strains parents experience. For example, school personnel can replace parents in supervising homework, or other children can walk together and socialize with youth with ASD.<sup>59</sup> Hence, children and adolescents need company and consistency, but these things do not necessarily have to be provided by parents.<sup>23,32</sup> Although parents often see themselves as gatekeepers in connecting their children with others, it is noticeable how few strategies parents recalled using to connect their children with peers. Service providers may focus on educating parents about how to support peer-to-peer interaction. Shared activities, such as walking together to school or working on homework in a group, increase social participation in children and adolescents with ASD.<sup>60</sup>

“Activities” comprised nearly a third of all parental strategies, indicating how frequently parents search for and adapt activities and motivate and inform their children about them. The poor executive functioning combined with less flexibility and poor problem-solving capacities seen in ASD might be one reason for this.<sup>61</sup> 15% of all parental strategies comprised informing and making children and adolescents knowledgeable about a topic. Adolescents with ASD expressed a high need to get information and become knowledgeable before they could participate in a community,<sup>23</sup> something that goes beyond parental strategies and can inform service providers and therapists as well.<sup>32</sup>

## STRENGTHS AND LIMITATIONS

Three strengths of this study are notable. First, it uniquely presents estimates of 45 activities regarding the participation of children and adolescents with ASD in three settings in Switzerland. Second, it describes for the first time parental contextual strategies tailored to children and adolescents with ASD which cover the whole phenotype of autism. Despite the wide use of the PEM-CY with various populations and research questions, parental strategies are rarely published, probably due to limited space in journals. Our paper's last strength lies in the combined use of contextual theory<sup>33</sup> with parental strategies, which makes the transactional interconnectedness between a person and contexts, setting, and environment for the sake of an enacted participation more transparent. Further reasoning can be found in the first part of this research.

In addition to our first qualitative analysis, we found it useful to apply the context definition of King et al.<sup>33,62</sup> for our second analysis. While doing so, we noticed that attitudes of others, institutional barriers, or social-economic situations were not reflected in the definition of contexts. These were only mentioned incidentally and did not interfere with our coding of parental strategies.

Several limitations of this study require consideration when interpreting the findings. First, as for all parent reports, the possibility of under- or over-rating is inherent.<sup>63,64</sup> Parents needed to score an environment they are fundamentally connected with. This might lead to participant bias. Next, possible selection bias—as described in part 1 in detail—might also be present for this second study. Although demographics of participants such as age, workload, or family constellations overall reflected a normative Swiss population, one demographic aspect in combination with the environment was noteworthy: 75% of the Swiss population lives in urban or suburban communities.<sup>65</sup> In our sample, only 42% of our participants were urban and suburban residents, while 57% of participating families were living in rural communities. It is yet unclear whether this is a voluntary bias, or whether parents with a child with ASD prefer rural environments. Fourth, as inherent in any cross-sectional study design, causality cannot be attributed and a direct connection between the two age groups cannot be supposed. However, we deliberately chose a purely descriptive analysis, and the results should be informative to health care providers and policy developers not acquainted with the PEM-CY construct.

## CONCLUSION AND FURTHER RESEARCH

The present study provides a diverse and in-depth look into environmental and contextual aspects for the participation of children and adolescents with ASD as seen from parents' point of view. Half of the parents from Switzerland saw more supports than barriers for their children's participation. However, barriers such as attitudes, social demands, or sensory qualities of the environment were described as less tangible and less changeable for parents. Parental perspectives on participation and their contextual strategies need to be considered in environment-based interventions to support the social participation of children and adolescents with ASD. This can simultaneously reduce caretaking-related strain in parents of children and adolescents with ASD.

More research with this transactional perspective on the interconnectedness between environment, context, and participation of youth with ASD is needed; environment-based intervention to increase their participation is also important.

## ACKNOWLEDGMENTS

We would like to express our sincere thanks to CanChild for the permission to use the PEM-CY(G), Dr. Andreas Bänziger for setting up the questionnaire on the online platform and providing support while we extracted and analyzed data, and Simon Renzler for advising on statistical analysis. We thank all organizations and individual persons for supporting data collection. And most of all, we are deeply grateful to the participating parents of children and adolescents for their time and efforts to share their daily experiences and provide insights into their desires for change.

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# CHAPTER 7

General discussion





## GENERAL DISCUSSION

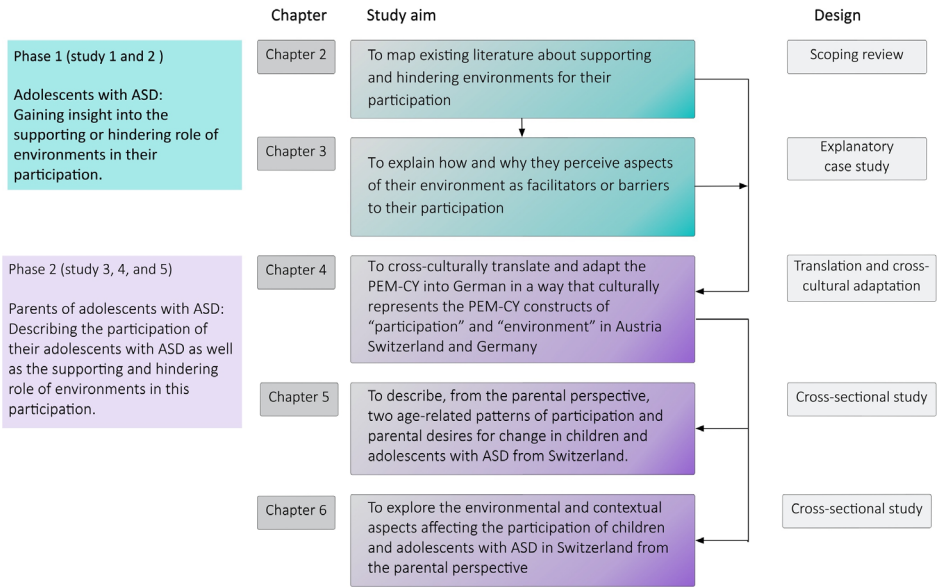
*Chapter 7 will first provide a summary of the results of the literature review and the four empirical studies to answer the two research questions. It will then reflect on the theoretical lenses used throughout the dissertation, the understanding gained about the participation of adolescents with ASD, the insight gained into the environment's role in their participation, and methodological considerations. The chapter will end with recommendations for research, practice, and education, as well as implications for society and adolescents with ASD and their families.*

## OVERVIEW ON FOUND RESULTS

*This subchapter (1) presents the research question, (2) presents the results of each of the five consecutive studies, and (3) briefly summarizes the results.*

This research sought to deepen our understanding of the role of environments as supportive or hindering to the participation of adolescents with ASD. Two subsequent research questions guided the two phases of the dissertation as portrayed in Figure 7.1. First, the role of environments as supportive or hindering to the participation of adolescents with ASD as described in the literature and by adolescents themselves was answered. Next, parental perceptions of the role of environments as supportive or hindering to the participation of their children with ASD was assessed; first, a measure was translated and culturally adapted, and then two studies were performed.

Figure 7.1 General outline of the study.



## THE ROLE OF ENVIRONMENT IN PARTICIPATION AS RETRIEVED FROM THE LITERATURE (CHAPTER 2)

The number of studies retrieved from different scientific disciplines confirmed the large volume of autism-specific research and showed that adolescents with ASD are often not explicitly examined. The final analysis of 31 studies represented adolescents from a broad autism spectrum and addressed the three ICF participation domains (d7-d9), mainly covering real and desired friendships, social relationships, leisure activities, and transition to work. The main ICF environmental domains researched were support and relationships (e3), attitudes (e4), and systems and policy (e5). We found a complex interrelation between adolescents' participation and their environment and summarized the role of the environment via three main themes and ten subthemes.

1. *'Providing security'* showed how environments have either a securing or intimidating effect on the participation of adolescents with ASD, which is greatly influenced by parents and familiar environments. When supportive, these social environments provide security through trusted relationships. They initiate participation, accompany the adolescents with ASD, and provide time, financial

resources, and regularity. Further, adolescents with ASD have a strong need to attend participation securely, and this security is built on information, knowledge, and preparation. The adjustable sensory qualities of the physical environment play an additional supportive role in providing security.

2. *'Helping to connect'* delineated how environments support or hinder social relationships or social activities. Adolescents with ASD want to be connected and to experience relationships, intimacy, and a sense of belonging. The social and attitudinal environment, family members, peers, friends, services, and staff all play a significant role in providing conditions and services that lead to connectedness and acceptance instead of separation.
3. *'Tension in participation'* summarized ambiguities regarding the participation of adolescents with ASD such as isolation or solitary participation, participation in disability-related groups, and the dilemma of normalcy and difference.

## THE ROLE OF ENVIRONMENT IN PARTICIPATION OUTSIDE OF HOME AND SCHOOL AS DESCRIBED BY ADOLESCENTS WITH ASD (CHAPTER 3)

An exemplary case study of six male adolescents with ASD found that participants viewed their participation experiences outside of home and school as social acts, regardless of whether these experiences were social or solitary. This informed us about their perspective on public or communal spaces in general. We learned that, for these adolescents, participation starts prior to attending, which influenced the title of the first theme: *'environmental prerequisites to attend participation'*. The five subthemes, (1) the company of trusted persons, (2) the presence of a nudging drive, (3) the provision of knowledge and information, (4) the presence of good vibes, and (5) a particular design to the physical environment, were necessary in combination to allow adolescents to attend and participate. For adolescents to achieve *'involvement and engagement in participation'*, the second main theme, we found that three concrete environmental strategies were helpful: (1) being approached, (2) becoming a group member, and (3) being acknowledged and gently guided.

## TRANSLATION / CULTURAL ADAPTATION OF THE PEM-CY (CHAPTER 4)

After thoroughly considering scientifically relevant measures to assess youth participation and environments, we chose the parent's reported Participation and Environment Measure - Child and Youth (PEM-CY). The already existent translation into



German posed difficulties regarding reliability, face validity, and cultural applicability. In collaboration with the developers, we perform a cross-cultural translation and adaptation process to develop a German version of the PEM-CY, suitable for three German-speaking countries (Austria, Germany, Switzerland). The linguistic and conceptual insights into ‘participation’ and ‘environment’ gained by think-aloud interviews with 15 parents lead to major equivalent changes in the PEM-CY(G) and challenged our understanding of normative participation. All four types of equivalent changes (semantic, idiomatic, experiential, and conceptual) were necessary to culturally represent the PEM-CY in these three countries without changing the measure’s construct. The PEM-CY(G) is now available for research, practice, and further validation.

## PARTICIPATION OF CHILDREN AND ADOLESCENTS WITH ASD AND PARENTAL DESIRES FOR CHANGE (CHAPTER 5)

This cross-sectional study described the views of 115 parents from Switzerland on the participation patterns of children and adolescents with ASD, combined with parents’ desires to change these patterns. The culturally adapted PEM-CY (G) was the primary measure used for the online survey. Children and adolescents’ participation patterns (diversity, frequency, and involvement) differed between home, school, and community settings. While both age groups participated most often at home, followed by school, community participation was low or nonexistent for both groups. School involvement exceeded participation frequency in both age groups, indicating higher involvement at school than in other settings. Notably, while children socialized frequently with other children outside of their classes, this type of socialization was drastically less frequent in adolescents. In the community, participation frequency was lower in adolescents than in children. However, involvement was similarly low in both groups.

Half of parents expressed a desire to change the participation of their children. We found three tendencies: (1) parents most frequently desired changes in the home setting, commenting on daily struggles with memory, motivation, initiation, physical support, emotions, and the need for sameness. Parents desired more independence, more insight into the necessity of activities, and more involvement. (2) Parents of adolescents expressed more desire for change in all three settings compared to parents of children. (3) Parents of both age groups wanted predominantly higher

participation frequency and involvement in all areas, with two exceptions: gaming and watching films. Over 40% of parents of adolescents wanted change in household chores, school preparation, and getting together with others in all three settings.

## ENVIRONMENTAL SUPPORTS AND BARRIERS TO THE PARTICIPATION OF CHILDREN AND ADOLESCENTS WITH ASD AND PARENTS' CONTEXTUAL STRATEGIES (CHAPTER 6)

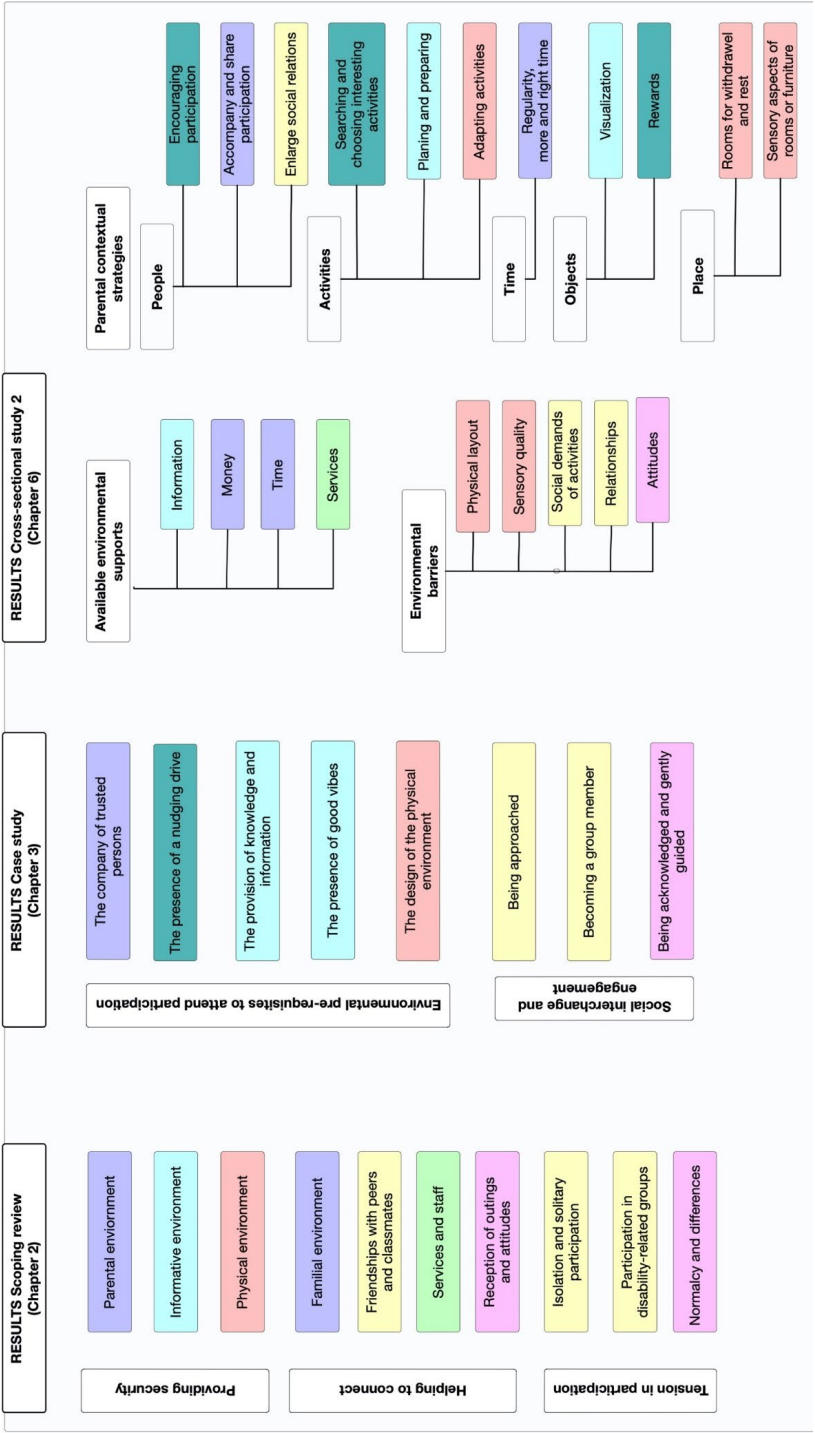
The final study used the same sample and methodology described in chapter 5 and examined parental views on supporting and hindering environments for their children and adolescents with ASD as well as parental strategies to support their children's participation. Results revealed that half of the parents in Switzerland perceived more environmental supports than barriers to their children's participation as assessed by the PEM-CY(G). Supports included aspects such as services, information, time, and money. In contrast, environmental aspects such as physical layout, sensory quality, demands of activities, relationships, or attitudes were seen as significant barriers to participation. In both age groups, 'sensory aspects' and 'social demands of activities' were the greatest barriers in all three settings. This was explicitly the case in the community setting, where environments were more flexible and less predictable. The other half of parents did not clearly describe environmental aspects as barriers or as support to their children's participation.

Parental contextual strategies were diverse and largely comprised of 'people' (41%) and 'activities' (37%), indicating the importance of the social environment and the need to adapt activities to the capacities and needs of children and adolescents with ASD. Both investigations revealed only minor differences between the two age groups, indicating that environments may stay the same during childhood and adolescence.

## SUMMARY OF RESULTS

The research described in this dissertation found seven environments essential for the participation of adolescents with ASD between 12 and 21 years of age: (1) parental and familiar environments, (2) social environments, (3) informational environments, (4) attitudinal environments, (5) physical environments, (6) nudging and motivational environments, and (7) environments with services and staff. Most of these environments were found in all three studies, which dealt directly with environments as portrayed in Figure 7.2.

Figure 7.2 Essential environments for adolescents with ASD.



blue: parental and familiar environments, yellow: social environments, turquoise: informational environments, pink: attitudinal environments, red: physical environments, dark green: nudging and motivational environments, and light green: environments with services and staff.

These seven environments seem to play a role before and during the participation of adolescents with ASD. Their central supporting role revolves around security and connection. As such, supportive environments play a more active role than hindering ones. Active refers to motivating, encouraging, extensively informing, reducing sensory overload, and accompanying children's participation. Parents and the environments created by parents and families are described as the most critical environmental factors for the participation of adolescents with ASD.

This dissertation further generated insight into the participation patterns of adolescents with ASD and developed a culturally adapted version of the PEM-CY for German-speaking countries.

## DISCUSSION

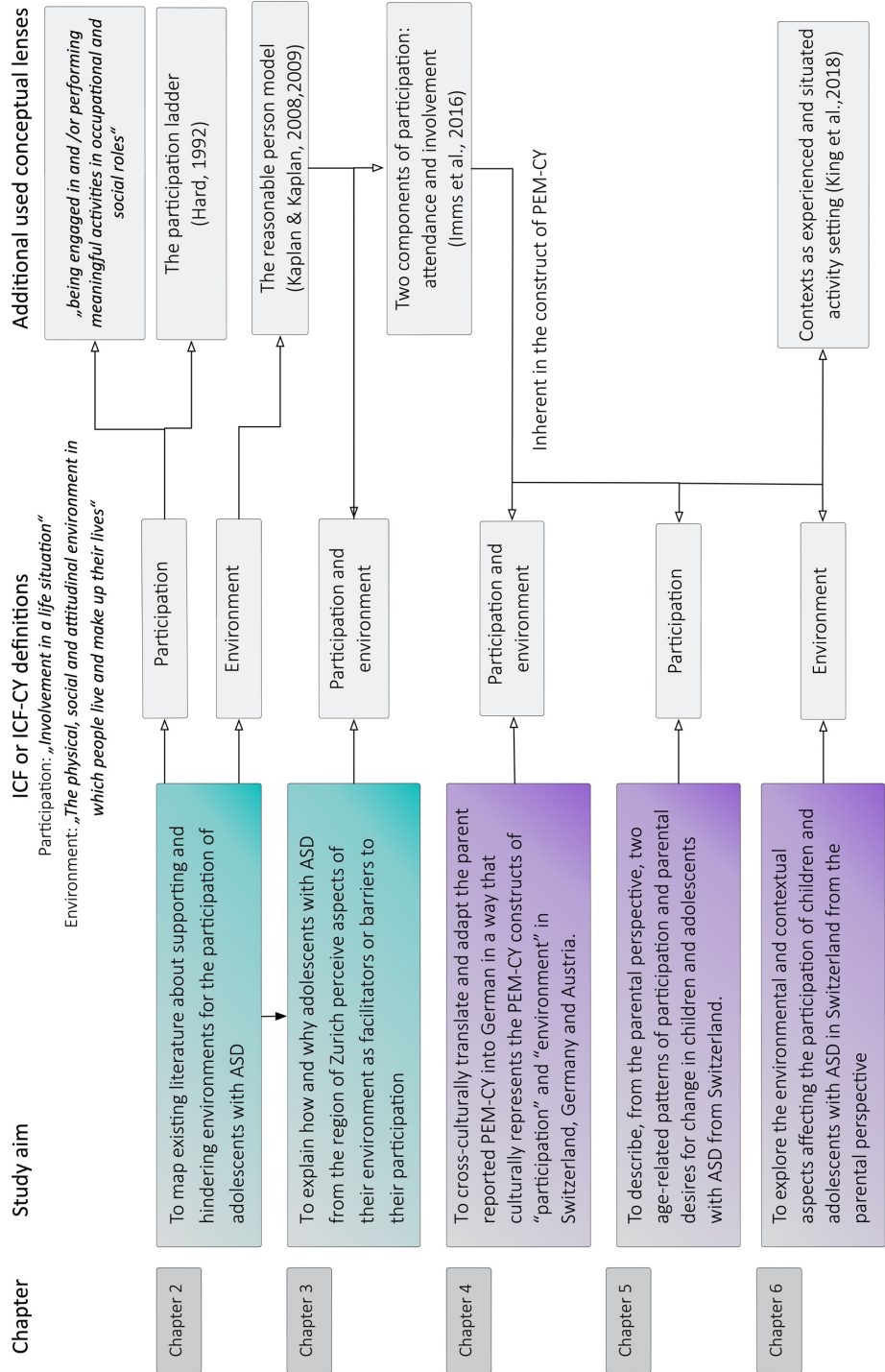
### THEORETICAL TRIANGULATION TO UNDERSTAND "PARTICIPATION" AND "ENVIRONMENT"

*This subchapter reflects on the theoretical lenses used for this dissertation and argues why during the process new ones were integrated.*

The International Classification of Functioning, Disability and Health (ICF)<sup>1</sup> and its respective child and youth version (ICF-CY)<sup>2</sup> framed the entire dissertation process, due to the two central concepts of "participation" and "environment." Although only a classification, ICF and ICF-CY have influenced widespread conceptual discussions and the development of instruments that are used in clinical contexts as well as for interdisciplinary communication.<sup>3</sup> As such, its use is positioned in this dissertation within a bio-medical and interdisciplinary scope, connected the support of adolescents with ASD to the United Nations (UN) convention of the rights of persons with disabilities.<sup>4</sup>

During the sequential process of this dissertation, additional theoretical lenses were used to complement the ICF definitions to understand the 'participation' and 'environments' of adolescents with ASD in more depth. Figure 7.3. delineates these by the different chapters.

Figure 7.3 Use of conceptual lenses throughout the dissertation.



ICF and ICF-CY in the scoping review (see Chapter 2) were helpful in two ways: First, they provided definitions for the two central concepts, such as *“involvement in a life situation”*<sup>2(p7)</sup> and *“the physical, social, and attitudinal environment in which people live and conduct their lives”*.<sup>2(p10)</sup> At the beginning of this dissertation, scientific research on the environment in combination with ICF was rare.<sup>5–7</sup> Five elements to understand a person-environment-relationship were discussed: (1) a person and her/his personal characteristics, (2) an external environment objectively described by an outsider, (3) the perceptions people have about their environment, (4) the process of interaction (between the two elements), and (5) the outcome of this relationship, measured according to the ICF framework for participation. The authors conclude that an explanatory model is needed.<sup>5</sup>

Secondly, the ICF classification with the connected domains allowed a comprehensive overview and supported clustering the literature into relevant aspects. As such, the scoping review could highlight areas of interest for adolescents with ASD: three ICF-participation domains (interpersonal interactions and relationships (d7); major life areas (d8); and community, social, and civic life (d9)), all inheriting a social or societal perspective,<sup>6</sup> as well as three ICF environmental domains (support and relationships (e3), attitudes (e4), and services, systems, and policy (e5)) were most relevant.

However, there are limitations to the ICF and the ICF-CY as others have described<sup>6,8–12</sup>; hence, the conceptual lens was widened at the beginning of the dissertation:

1. First, ‘participation’ as a relational concept can only be understood and assessed by considering the role expectations held by subgroups, the community, or overall society, as well as the social setting and environment in which the roles are to be performed.<sup>6</sup> As an occupational therapist convinced of the importance of ‘social roles’ and ‘occupational roles,’ I expanded the definition of ‘participation’ by adding *“being engaged in and/or performing meaningful activities in occupational and social roles”* throughout the dissertation. Adopting this view, three prominent relational roles of adolescents with ASD emerged from the literature: student, peer, and friend. The literature rarely covered family-related roles, such as son/daughter or sibling. It might be that a systemic family approach is still rare in autism research.<sup>13</sup> However, parents from Switzerland wished their children with ASD would take on more domestic roles and expand their participation (see Chapter 5).

2. The overlapping concepts of ‘participation’ and ‘social participation’ were the next concern.<sup>14,15</sup> I was cautious about focusing solely on ‘social participation,’ as it was unknown whether and how adolescents with ASD want to participate socially.
3. Due to the scarcity of research on the perspectives of adolescents with ASD themselves,<sup>16</sup> it was not known whether participation is a desired outcome for them. Conceptually, this points to the difference between subjectively experienced and objectively observable participation and environments, which are not addressed in ICF and ICF-CY.<sup>17</sup> Viewing adolescents with ASD as a vulnerable group, as in Hart’s *‘participation ladder’*, supported my reflections about making decisions and interpreting the power adolescents with ASD were given (or not given).<sup>18</sup> Hart explicitly addressed the disempowerment or empowerment of young persons by adults. By using this lens, I could question whether the importance of friendship for adolescents with ASD is sufficiently acknowledged in current service provision and autism-related research (see Chapter 2).
4. Last, although supports and barriers are both qualifiers used in ICF and ICF-CY regarding the environment, clarification of these value-laden concepts was missing. How could support be identified when there were no definitions for the qualifiers? By including Kaplan’s *‘reasonable person model’* with its description of supporting environments, we could qualitatively gain insight into a securing and calming person- environment transaction.<sup>19,20</sup> Supportive environments allow cognitive mapping, involvement, and support competency. The authors looked at a wide variety of environmental aspects such as architecture, space, light, social culture of information, nature, and urban planning. This model influenced the third subtheme, ‘informational security,’ in the scoping review (see Chapter 2); it became one of the themes of the case study (see Chapter 3) and was the most often-mentioned contextual strategy parents applied to support the participation of their children with ASD (see Chapter 6).

During inductive thematic analysis in the explanatory case study (see Chapter 3), it emerged that participation of adolescents on the autism spectrum does not begin with ‘involvement in a life situation’,<sup>2(p7)</sup> but much earlier. Participation came sequentially into the lives of these adolescents along a timeline, beginning with the first idea about an activity, followed by phases of motivation and planning, knowledge transfer, and company, until the first moment of attendance, which slowly and hopefully transitioned to experiencing involvement and engagement. This confirmed that

‘attendance’ and ‘involvement’ represent the non-categorical perspective of participation,<sup>10</sup> as described in the family of participation-related constructs (fPRC),<sup>12</sup> which have recently been acknowledged more when describing participation.<sup>21</sup> Imms and co-authors<sup>10</sup> defined ‘attendance’ as being there and measured by the frequency or range of diversity of activities; ‘involvement’ was defined as experience combined with engagement, motivation, persistence, and affect. ‘Attendance’ and ‘involvement’ are further assessed by the Environment Measure-Child and Youth Version (PEM-CY)<sup>22,23</sup> which was used in Chapter 5 and 6.

After the analysis of the literature (see Chapter 2), the overlaps between the ICF domains of social relationships, classified simultaneously under participation (d7) and environment (e3), could not be solved. The friendship of a girl with ASD and her peers may serve as an example.<sup>24</sup> Their relationship is interconnected and reciprocally created by each of them. Also, parents represent simultaneously the social environment of adolescents with ASD and were asked in the last study to describe the environments of their children with ASD. Influenced by feedback gained from think-aloud interviews (see Chapter 4), I decided to use an additional context-specific lens to grasp this transactional relationship. Contexts as situated life settings are personal, considered from the perspective of the person participating, and are related to the people, place, activity, objects, and time in which the participation is set.<sup>25</sup> King and colleagues argue that *“we need to understand the nature of specific contexts and the transactional processes they engender, not just consider “environment” as an amorphous, undifferentiated concept essentially meaning “everything outside the person” – in other words, as a separate entity often thought of in terms of ecological levels (e.g., family, organization, policy environment).”*<sup>25(p1837)</sup>

The dynamic interplay between environment and participation is described widely regarding disabilities.<sup>5,6,8,12,26,27</sup> Both concepts are so broad that researchers first need to limit the possibilities to those aspects that potentially *“play a role in limiting or enhancing the functioning of individuals with defined impairments. To do so, we need a theory of how environments affect functioning, however unsophisticated that theory (or collection of theories) may be.”*<sup>6(ps33)</sup> This dissertation did not aim to develop a theory. Still, it showed how a collection of theories could support our understanding of the importance of environments to the meaningful participation of adolescents with ASD in a mutual way.



## MEANINGFUL PARTICIPATION IN ADOLESCENTS WITH ASD

*This subchapter stresses the importance of social roles for the participation of adolescents with ASD, reflects on the selection of a measurement instrument to assess participation, points to highlights of setting-specific participation patterns of adolescents with ASD, and ends by reflecting on normative and subjective meaningful participation.*

The literature on participation for adolescents with ASD covered (see Chapter 2) three ICF and ICF-CY participation domains describing to a similar extend interpersonal interactions (d7) and major life areas (d8) and to a minor extend community, social, and civic life (d9); all were judged as being sociable and/or societal.<sup>11</sup> The found importance of the role of a friend as the one that adolescents with ASD long for is similarly described by others,<sup>28–32</sup> and mirrored by the high amount of desires of changes by Swiss parents to increase ‘*getting together with peers*’ (see Chapter 5). Referring to the found ambiguities regarding the participation in disability-related groups (see Chapter 2) it was also found in other disabilities<sup>33</sup> that participation in disability-related social groups and friendships between adolescents with ASD allows them to form a positive identity and escape the constant pressure to fit in.

Participation measurements for youth with ASD are rare and their validity doubtful.<sup>34,35</sup> Additionally, the restricted participation of individuals with a disability has often been described by comparing their participation patterns to a general population, but this might be questionable due to the non-normative nature of participation in adolescents with ASD.<sup>36</sup> We finally decided to use the PEM-CY,<sup>22</sup> as it combines participation and environments as described from the subjective perception of parents. Unfortunately, until now, a PEM-CY-based self-assessment for adolescents and younger adults was nonexistent. Proxy and self-reports are not identical in this group of adolescents.<sup>37,38</sup> However, contrary to a measure with a normative scaling, such as the ‘Child and Adolescent Scale of Participation (CASP),<sup>39</sup> by asking parents to compare their children’s participation to that of typically developing children, the PEM-CY assesses frequency and involvement subjectively according to activity groups such as self-care or organized physical activities. Results encompass aspects of participation balance or imbalance, which are not precisely normative. This was the reason to refrain from describing adolescents with ASD and those without ASD (see Chapters 5 and 6) as often

is done in the literature.<sup>40–43</sup> Instead, we decided to document participation patterns and parental views about desires for change in the two age groups.

Participation patterns of adolescents with ASD in Switzerland were described in different settings as diverse (see Chapter 2 and 5) and different (see Chapter 5) with regards to participation frequency and involvement.

1. The home setting is the place adolescents participate most frequently. Similar as in adults with ASD<sup>44</sup> this is the setting they feel most safe and socially connected. However, we found low involvement rates in activities such as ‘getting together with others’, ‘household chores’, ‘school preparations,’ and ‘homework’ as described by parents. It is possible that the parental burdens of motivating, guiding, and teaching adolescents with ASD to achieve participation have not been investigated with enough urgency by researchers or addressed with enough engagement by service providers.<sup>45,46</sup> To follow this further, the perspective of adolescents with ASD themselves (and possibly without being influenced by parents)<sup>47</sup> is needed. As described by others,<sup>48</sup> Swiss parents also wanted to decrease the use of electronics at home. Considering the increase of media use in adolescence in general, it is open whether this wish of parents reflect an overuse of media or a compensation of missing other participation fields as reported in adults with ASD.<sup>49</sup> Access to information and communication channels can provide young people also with new opportunities to participate in and contribute to society but also introduce health challenges such as social isolation resulting from persistent use of internet.<sup>50</sup>
2. At school, ‘classroom activities’ and ‘getting together with other children’ had a high frequency of participation in adolescents with ASD, while participation involvement varied considerably. A recent survey in Switzerland about school conditions during the pandemic revealed the importance of peer relationship, attitudes of peers and joined activities at school for students with ASD and their parents.<sup>32</sup>
3. In the community, participation in adolescents with ASD in Switzerland focuses on ‘neighborhood outings’ and ‘unstructured physical activities,’ while most other activities were with low or not existing frequency and involvement, as reported elsewhere.<sup>40,48,51–53</sup> This contrasts with the descriptions of our case study (see Chapter 3), where adolescents with ASD performed activities outside of school

regularly and consistently, but pointed to the special conditions to prepare their participation attendance and engagement.

Participation for adolescents with ASD might not begin with ‘involvement in a life situation’,<sup>2(p7)</sup> nor with the act of attendance;<sup>10</sup> it may chronologically, mentally, and emotionally begin before this, as this dissertation elaborates. Preferences and choice are significant predictors of participation<sup>12,26</sup> and apply to adolescents with ASD as well.<sup>16</sup> Hence, as shown in all our empirical studies, they do not choose to participate automatically. Addressing their interests and motivation, offering choices and knowledge, and presenting organized and detailed plans were highly important in the literature review (Chapter 2), adolescents’ descriptions, (Chapter 3), and parents’ strategies (Chapter 6). The UN Disability Rights Convention recognizes the importance of autonomy for persons with disabilities, including the freedom to make their own choices.<sup>54</sup> This is inherent in our understanding of participation. Adults with disabilities viewed participation as an *“expression of their values rather than as a defined preset or normative set of activities.”*<sup>26(p1449)</sup> Theoretical discourses also deal with normativity.<sup>17,36,55</sup> This dissertation indicates that the participation of adolescents with ASD might not be normative and agrees that *“very different patterns of participation can still reflect full participation”*.<sup>26(p1459)</sup> Other authors pointed to person-based elements for meaningful participation: having fun, experiencing success, having a sense of belonging, experiencing freedom, and developing identity.<sup>56</sup> Ingredients for meaningful participation for adolescents with ASD in this research were the individually-perceived correct combination of shared and solitary activities, performed persistently and with high involvement. This confirms beginning evidence that willingness and persistence predict engagement in participation.<sup>10</sup> The three cases at the beginning of this thesis—Marc enjoying concerts with his girlfriend, Phillip being proud of being a member in the fish club, and Luc coming to taekwondo training persistently despite being neglected or rejected by others—are examples of meaningful participation in adolescents with ASD.

## THE ROLE OF ENVIRONMENTS IN PARTICIPATION OF ADOLESCENTS WITH ASD

*This subchapter presents assumptions about the role of the environment regarding the participation of adolescents with ASD as described in this dissertation, gives insight into the role of environment, presents seven essential environments for the participation of adolescents with ASD, and reflects on some of the difficulties of measuring environments.*

Environments, enacted in settings (such as the community or at home) and concrete contexts (such as restoring in bedrooms or travelling with public transport and using a bus station) are part of every moment of participation—even when participation is mentally imagined. Their role as supporting or hindering is primarily indirect, less visible, multifaceted, and complex. This dissertation does not measure the amount of support or hindrance but directs attention towards the responsibility of the environment regarding the participation of adolescents with ASD. The central roles of environments for adolescents, regardless of the severity of autistic traits or age, are **‘providing security’** and **‘helping to connect.’**

The environment’s securing role is related to how the environment provides adolescents with personally perceived security. Within the ‘restorative person model,’<sup>19,20</sup> restoration, mental mapping, and a feeling of acceptance are essential attributes. For adolescents with ASD, these securing attributes can reduce anxiety<sup>57</sup> and stress,<sup>58</sup> and in severely affected youth with ASD, the amount of repetitive and restrictive behavior.<sup>59</sup> We found that the parental, informational, and physical environments were the most frequently researched securing environments. Specifically, the home setting is described as essential to delivering security and protection for persons with ASD.<sup>44,60–62</sup>

‘Helping to connect’ addresses how environments help create and strengthen social relationships with others and contribute to friendship and a sense of belonging among adolescents with ASD. The literature review indicated that this is what adolescents long to for. It has also been recently reported in other research.<sup>16,32</sup> Swiss parents wished for more peer relationships for their children and adolescents. Familiar environments (here understood as the circle of siblings, extended family, and friends) interact with peers and classmates, services and staff, and the reception of outings and attitudes to

play a central role in supporting or hindering the social connections of adolescents with ASD. Because of this prominent role, the social environment of adolescents with ASD has the most significance for the social participation of adolescents with ASD.

As portrayed in Figure 7.1, seven environments are found to enact these two central environmental roles in the participation of adolescents with ASD. These are discussed as follows:

1. **Parental and familiar environments** are profoundly intertwined with adolescents with ASD and mutually influence each other. Gray<sup>63</sup> reported that parents of children with ASD try to construct a normal family life by balancing the needs of all family members and their own belief system.<sup>64</sup> This makes an ecological approach imperative.<sup>65</sup> Parents, and to a minor but not unimportant extent, siblings and wider families, are the most important, most socially relevant, and most trusted persons to adolescents with ASD respective to their participation. Adolescents with ASD need the company of trusted persons. This seems to be essential to discovering new participation opportunities and overcoming anxiety specifically in the community.<sup>52,66</sup> The implicit knowledge of parents and family members on how to support adolescents with ASD is both a resource and a challenge<sup>61,67,68</sup> and adds to their managing tasks as parents, family managers, and individuals.<sup>69,70</sup> Honoring the perspectives of parents and better addressing their needs and those of their families have emerged as clinical and policy priorities to support the participation of adolescents with ASD.
2. **Social environments (mostly peers and friends)** describe the environment that adolescents on the autism spectrum experience to some extent at school; they experience this much less outside of school, in neighborhoods, or in communities. The role of a friend is one that adolescents with ASD and their parents long for.<sup>32</sup> It is essential to fortify efforts to develop and strengthen social (and specifically peer) environments for adolescents with ASD.<sup>71</sup> Although parents wish their children would socialize more, strategies to support this goal combined with their own social-support seeking strategies are reported to be reduced.<sup>72,73</sup> Given the importance of feeling socially connected for persons with ASD,<sup>32,44</sup> it might be questioned whether this is sufficiently acknowledged by current service providers and in autism-related research. Establishing and supporting social peer-focused environments, such as those presented by Jones,<sup>74</sup> are essential to the coaching of parents and in school trainings,<sup>75</sup> leisure services,<sup>76</sup> and communities in general.<sup>52</sup>

Addressing autism-friendly attitudes in peers is another option.<sup>77</sup> Attending disability-related social groups might allow adolescents with ASD to form a positive identity and to escape the constant pressure to fit in.

3. **Informative environments** play a role before and during the participation of adolescents with ASD. In providing information and knowledge, they compensate for a world that is challenging and often unpredictable for persons with ASD.<sup>70,78</sup> Due to substantial differences in how the brains of persons with ASD predict environments (specifically social environments<sup>79</sup>), intensive, precise, repetitive, and rule-focused information supports security, social understanding, and ease, therefore increasing the participation of adolescents with ASD.<sup>71</sup>
4. **Attitudinal environments** address normalcy and differences, disclosure, and the feeling of being accepted and acknowledged despite differences. The sociologist Erwin Goffman<sup>80p3</sup> described stigma as a “*situation where a “individual is disqualified from full social acceptance,”* and thus refers to it as an “*attribute that is deeply discrediting.*” In adolescents with ASD, negative attitudes hinder them twice by being enacted on adolescents directly and through parents and families who also endure negative attributes.<sup>81</sup> The disqualification is often less outspoken and subjectively perceived differently.<sup>82,83</sup> Attitudes towards persons with ASD need to be examined closely on a societal level, such as through common narratives and understanding how diversity is dealt with when it is normalized.
5. **Physical environments** often have a disturbing and interrupting effect on adolescents with ASD due to different sensory processing.<sup>84</sup> Providing agency to modulate them was found to be supporting. Even in home environments—which parents play a significant role in creating—did parents in our study perceive a high number of physical barriers. A combination of person-centered and systemic understanding is needed to address this at home<sup>60</sup> or in the community.
6. **Nudging and motivational environments** acknowledge that attendance and involvement in participation is not naturally experienced in adolescents with ASD. Their motivation, interest, and willingness can be nudged. Variables such as choice, adaptation to interests, and natural reinforcers are shown to be effective in settings such as in schools<sup>85</sup> and in severely affected youth with ASD.<sup>59</sup> Specifically for adolescents with ASD and lower intellectual capacities, such self-determination qualities must be nurtured.<sup>86</sup> Although mainly interpersonal, there are also system and service components. More environmental flexibility to address these motivational aspects is needed.

7. **Environments with services and staff** include individuals such as teachers, sports coaches, or security personnel, and systems such as health care providers, sports organizations, or social services. The inclusion of diverse people is a societal task. Parents of children with ASD reported that advocacy and empowerment support participation and coping strategies.<sup>87</sup> However, the amount of support and service delivery an adolescent is given depends on parents' attitudes and engagement.<sup>88</sup> This is a question of social justice: services and staff support of adolescents with ASD should be individualized but equal.

The participation of Marc, Phillip, and Luc (the three adolescents portrayed in the cases at the beginning of this dissertation) was possible because they had many different environmental supports. They were enacted by friends, parents, and sport coaches and involved respect, company, and engagement; systems and organizations were also involved, adapting and allowing adolescents to be "normal" while still being different.

Measuring environments poses specific difficulties. Besides PEM-CY, I only found one measure for assessing participation and environments for children and adolescents together. The European Child Environment Questionnaire (ECEQ) measures the extent to which the environment facilitates or hinders participation among children with cerebral palsy.<sup>89</sup> As this the measure has only three general domains (physical environment, social support, and attitudes), I felt the PEM-CY to be more useful for this dissertation. However, even classifying environmental aspects with ICF and ICF-CY appears to be complex. Theoretically, three coding options are described:<sup>6</sup> (1) environmental factors are coded alone, without relating these codes to activities and participation; environmental factors are (2) coded for the ICF component of activity and participation generally; and (3) environmental factors are coded in combination with capacity and performance qualifiers for each activity and participation domain separately. For the literature review (see Chapter 2) the second option was used. In the environmental section, the PEM-CY uses the first option in combination with the three settings of home, school, and community. During the think-aloud interviews (see Chapter 4) about the PEM-CY, parents described their strong desires to connect environmental factors directly with single activities, thus opting for the third option.

There is a need to develop further environmental-based measurements for children and adolescents. ECEQ and PEM-CY provide insight into the existence of environmental barriers or supports to their participation. For further development, the construct of

the Craig Hospital Inventory of Environmental Factors for Children – Parent Version (CHIEF)<sup>90</sup> might be interesting. For each of ten environmental items, three scores are obtained: (1) the frequency of encountered barriers, (2) the extent of the problem a barrier typically presents, and (3) a frequency by magnitude product score, indicating the overall impact of the barrier. As such, the magnitude of supports and barriers, similar to how they are classified in ICF and ICF-CY, can be obtained.

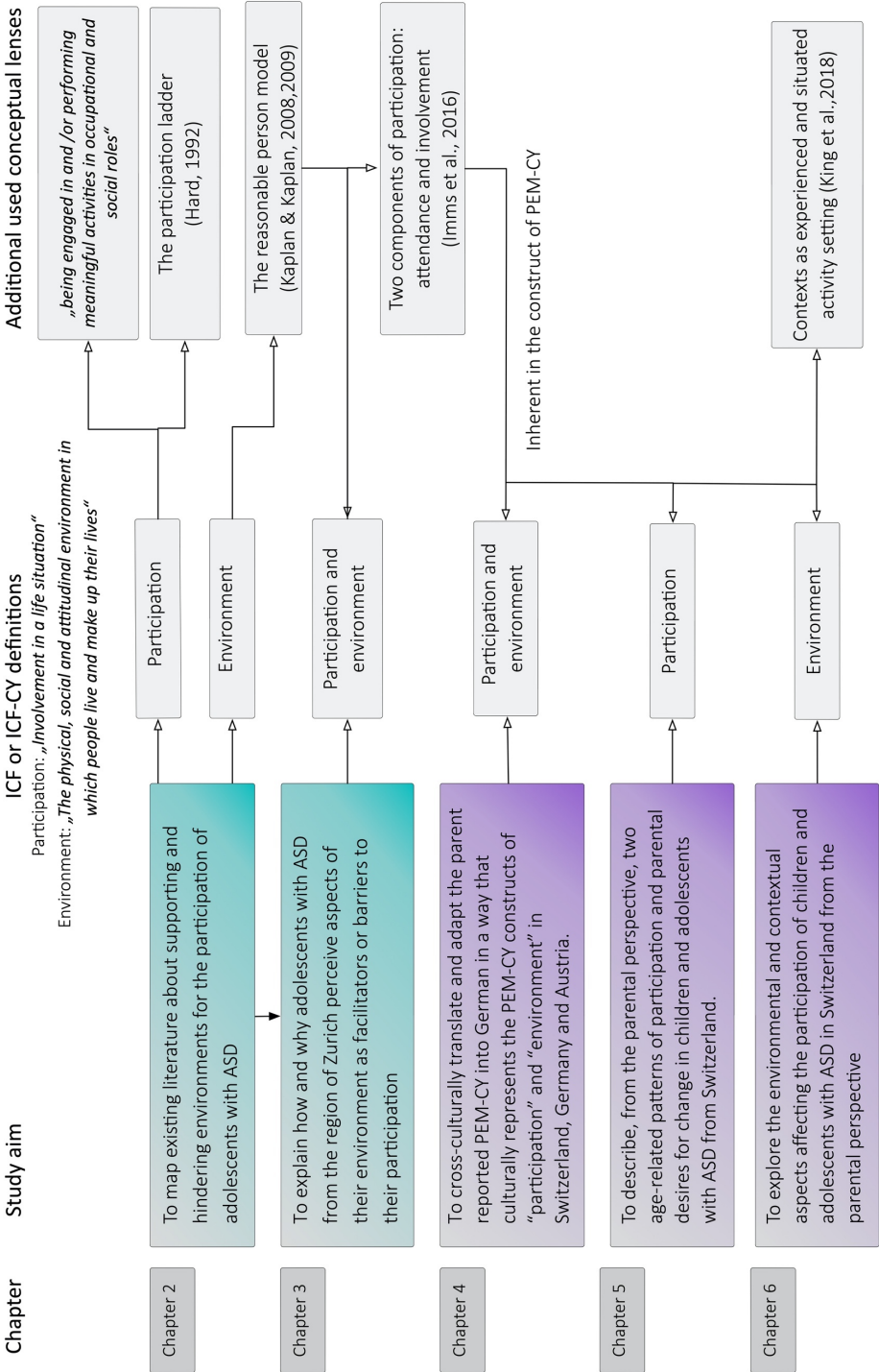
## METHODOLOGICAL CONSIDERATIONS

*This subchapter reflects on the methodologies used in this dissertation and presents three strengths and three limitations. Figure 7.4 gives an overview of the methods and methodologies used as well as on the adolescents with ASD or significant others involved.*

The first strength of this dissertation is the use of mixed-methods research, combining quantitative and qualitative methods.<sup>91–93</sup> Specifically, it is a complementary mixed-methods study, as qualitative and quantitative results supplement each other.<sup>94</sup> Three of the five individual studies (see Chapters 2, 5 and 6) collected qualitative and quantitative data and analyzed it accordingly.<sup>95</sup> Different perspectives (such as the literature, adolescents with ASD, and parents) were combined using different designs, such as a literature review (comprising 52% qualitative and 48% quantitative studies), a case study, and cross-sectional designs. The diversity of research methods was necessary given the relative scarcity of the interdisciplinary topic under research.<sup>96</sup> By applying a mixed-methods design, we obtained complementary results describing the same experience as well as associations between each individual study and the others,<sup>97</sup> which is also referred to as triangulation.<sup>98</sup> Some researchers demand an elaborate mixed-methods procedure merging data and analysis.<sup>99</sup> We published the five studies independently and merged the results with the seven essential environments.



Figure 7.4 Use of conceptual lenses throughout the dissertation.



The methodological developments that occurred during the planning of the dissertation can be considered a second strength. We applied a sequential process in which results from one study supported the design and the theoretical choices of the next one. Sequential processes are commonly used in health science mixed-methods research.<sup>98</sup> An example of this chaining was the use of three theoretical frameworks under ‘environment,’ starting from a wide angle using the ICF domains and moving to an interaction model<sup>19,20</sup> and then to a personalized context setting,<sup>25</sup> which represents a continual deepening to fulfill the main aim of the dissertation: namely, to elaborate the role of environments in the participation of adolescents with ASS. Additionally, this sequential process was fueled by pragmatic issues to meet the needs of policymakers and practitioners.<sup>100,101</sup>

A further strength of this dissertation is how it exclusively uses the perspective of adolescents with ASD or those of their parents (except for the scoping review, with 8% perspectives from peers). Inclusive health research can become more responsive to users’ needs. It further increases political legitimacy, decision quality, and acceptance of research outcomes.<sup>102,103</sup> Adolescents with ASD are a hard-to-reach research population<sup>104,105</sup> due to their age and communication difficulties. Commonly reported motivators to participate in research projects such as information access, economic gains, altruism, scientific advancement, expected therapeutic benefit, personal satisfaction, and health issue activism<sup>106</sup> may only partially apply to adolescents with ASD. In our scoping review, only 18% of all informants were adolescents with ASD. During the case study of 8 adolescents with ASD, the risk of patronizing them was on my mind. Therefore, information gathering was specifically careful and parents were included during the data gathering phase.<sup>54</sup> Adolescents received written explanation in cases others felt bothered by taking photos. Involving parents and their perspectives (see Chapters 4-6) reflects family-centeredness and is a consequence of seeing parents as the most important factor in the environment for children and youth with disabilities.<sup>107</sup>

This research also has some limitations. First, additional in-depth with a more profound understanding on supporting and hindering environments could have been reached by using a phenomenological or ethnographic approach. I refrained from this as opting for the canton of Zurich as a single case gave a more generalizable view of supporting and hindering environments. Due to the prolonged time adolescents with ASD need to

develop trust and confidence in a person,<sup>16,108</sup> the academic time frame was judged as being too challenging regarding the hurdles described by adults with ASD.<sup>109</sup> Next, I only presented descriptive results and refrained from associations and relational results such as analyzing the mediating role of environmental factors for the participation of adolescents with ASD. Reasons for this decision included the novelty of data from Switzerland and the conviction that descriptions are the first step to understanding a phenomenon. Another reason was the relatively small number of participants in the cross-sectional studies and the scaling<sup>110</sup> used in the PEM-CY (G), which was less favorable for using inferential statistics or calculating effect sizes.<sup>111</sup> Another limitation is that I decided against involving a reference group of healthy adolescents or parents, which reduces further generalizability.

Another limitation is that I did not involve (besides parents) other socially important persons for adolescents with ASD, and possibly missed expanding perspectives to those of socially relevant environments such as peers, friends, siblings, or grandparents. However, without using the parent-reported PEM-CY (G) as a measure, no other suitable measure combining participation and environments could have been used. I also did not find a suitable self-report measure for adolescents with ASD.

Finally, the research had little involvement of adolescents with ASD in the form of participatory action research<sup>112</sup> and had no parent advisory panel nor community organizations to collaborate with beyond recruitment. Financial shortages, time constraints, academic requirements, and overburdening of stakeholders were the most critical barriers we faced.<sup>102</sup> Moreover, participatory action research or even community-based research<sup>113</sup> is rather unknown in Switzerland. In retrospect, I think three adults with ASD contributing to the valorisation (see Chapter 2) and another person with ASD providing feedback on an interview guide (see Chapter 3) were not enough to give persons with ASD a real strong voice.<sup>114</sup>

## RECOMMENDATIONS

*This subchapter presents recommendations with a primary objective of serving adolescents on the autism spectrum and their parents and families. Six stakeholders will be addressed: (1) the scientific community (including further research); (2) practitioners; (3) educators; (4) community planners, architects, and designers; (5) service managers and politicians; and (6) adolescents on the autism spectrum and their parents and families.*

**The scientific community** can integrate environments, settings, and contexts systemically into their understanding of adolescents with ASD and their functioning and participation. Conceptually it should be acknowledged that participation is non-normative. Instead, supportive and hindering environments should be used to improve the situation of adolescents with ASD. Specifically, family-centered research should focus more on the needs of parents, siblings, and trusted persons to support adolescents' participation rather than using these people as side-therapists or service deliverers. In terms of concrete suggestions, I suggest four areas for further research:

1. Longitudinal research is needed to disentangle participation from development in children and adolescents with ASD and to obtain further knowledge about this important phase of young people's lives. Trajectories of participation might also be researched by describing changing roles in different environments, settings, and contexts.
2. Environmental-based interventions to increase the participation of adolescents with ASD should be developed based on the current research and should be accompanied by research on novel, feasible interventions. As with children with physical disabilities, interventions should consider that time and persistency might be important to success as well as parental involvement.
3. Due to the importance of the social environment for adolescents with ASD, research on creating and maintaining peer friendships for adolescents with ASD as well as their community participation should be pursued. The impact of supportive attitudes towards persons with ASD should be included in this research.
4. Future development of sensitive, setting-specific assessments of participation and environmental factors will be important. The judgments of adolescents with ASD themselves and their drives and willingness to participate are important features to consider.

**Therapists, service providers, and school staff** need to learn and practice changing environments and contexts for adolescents with ASD to support their participation actively. Specifically, the need for vivid peer-friendships should be acknowledged and nurtured by applying (for example) peer-mediated interventions or shared common interests.<sup>115,116</sup> Beyond company and a nudging drive, the provision of knowledge and information seems to be a powerful tool to support participation. Therapists, service providers, and school staff need to promote a peer culture that has a positive attitude towards the participation of adolescents with ASD; they must also combat stereotypes

and bullying. Further, secure attendance and involvement in participation in the community need to be a shared responsibility between therapists, service providers, and school staff.<sup>52</sup> This would also practically support parents and families.

**Education of professionals in health, education, and social work**, who will deal in the future with adolescents on the autism spectrum and their families should focus to teach about the importance of participation for the health and wellbeing of these young people. Students of fields such as occupational therapy, psychology, medicine, or social work need to learn far more about the impact environment has on participation. Students should actively be taught how to employ the powerful tools of the seven found supportive environments and contexts. Using these tools, they can enable or maintain the participation of adolescents with ASD, practice shared solution searching, and understand that the responsibility for success is combined between adolescents with ASD, their parents and families, and their environments.

**Community planners, architects, and designers** need to understand how physical and attitudinal environments shape the participation of individuals with ASD and their families and how they contribute to an inclusive society. Specifically, three aspects are worth mentioning. First, noise reduction will not only serve persons with ASD. It places environmental stress on all of society. Discussion and problem-solving regarding this issue are already occurring in fields such as e-mobility or architecture. Second, by referring to the restorative model,<sup>19,20</sup> this dissertation recommend to consider the need to combat stress and fatigue by providing restorative areas for individuals to calm down. Third, informative environments support orientation for more than just adolescents with ASD. However, involving people with ASD in the process of developing information and visual signaling may enrich further improvements and can promote awareness of the capabilities and contributions of adolescents with ASD to society.

**Service managers and politicians** should acknowledge the effects and efforts of parents more explicitly. With regards to their important role in the participation of their disabled children,<sup>117</sup> parents need to be actively involved in any kind of intervention or placement,<sup>118</sup> as shared decision making is effective for children of all ages.<sup>119</sup> There is even emerging evidence that shifting leadership regarding services provision into the hands of parents leads to stronger coherence in family values, engagement, and empowerment.<sup>120</sup> To achieve this, the competencies of staff to involve parents and

families into any decision about service delivery must be strengthened. Additionally, service regulations need to be more flexible and family centered. An example might be the school selection process: at least in Switzerland, there is a need to partner more with parents of adolescents with ASD. 17% of children with ASD in our research attended private schooling, which is financed by parents when they can afford measures intended to provide their children with adequate schooling that public schools cannot provide. If society, politicians, and service managers want independent, productive, and healthy adults with ASD, supportive environments for these adolescents must be enhanced, such as by providing strengths-based supportive programs outside of school.<sup>121</sup> Administrators have to take into account the fact that these adolescents need more time to adjust to change, more adaptations to their schooling, and a more positive learning environment<sup>122</sup> than other adolescents. Services should be prepared for these needs and should establish competencies to support adolescents with ASD, especially those with parents and families of low SES (social economic status) or who are otherwise challenged (single parents, those with many children, immigrants, and those with psychological problems), as these individuals have less ability to support their adolescents with ASD from an environmental perspective. To address the importance of attitudinal environments, political dialogues need to target reduced participation and stigma towards persons with disabilities more explicitly.

**Adolescents on the autism spectrum, their parents, and their families** have been confirmed through this study that there is a shared responsibility between environments and youth with ASD themselves regarding successful participation. Due to the intertwining of environment and individuals, adolescents and parents have the right—and even the duty—to demand support from different environments and contexts as outlined in this dissertation. Regardless of the macrostructures of society, raising a child with ASD is connected to time constraints and restricted social lives for families.<sup>123</sup> It is therefore strongly recommended that parents and families widen their own social networks for the sake of their children.<sup>65</sup> Grandparents,<sup>124,125</sup> siblings,<sup>126,127</sup> and wider family and peers<sup>128</sup> should be involved early, preferably beginning in the home context. Next, it is recommended that adolescents with ASD attend strengths-based supportive programs<sup>121</sup> lead by others and that they be gently pushed into participation in contexts other than the home.<sup>122</sup> This dissertation shall strengthen parents' conviction that they play a major role in the most important environments for

their children with ASD. Whether this responsibility is perceived as a joy or a burden<sup>67</sup> depends partly on how active environments are supporting these adolescents' participation. Finally, adolescents with ASD need to learn how to express their needs and wishes so that environments can become responsive and adapt accordingly.

## CONCLUSIONS

The goal of this dissertation was to deepen the understanding the role of environments and contexts in the participation of adolescents with ASD. Participation for these adolescents is a combination of solitary and social participation and is not normative. This dissertation highlighted the importance of parental and family environments, the need for company during participation, the special role of information and knowledge for adolescents with ASD, the role of physical aspects of the environment, and the need for motivation and nudges to connect and engage socially. Combatting negative attitudes is a further aspect of an engaged, active, and supportive environment. The main role of environments is to feel secure and help adolescents to connect. As such, supportive environments seem more important for the participation of adolescents than the simple removal of barriers.

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# CHAPTER 8

Summary  
Zusammenfassung







## SUMMARY

Adolescence is a period of physical adjustments and role changes within the family and society. Adolescents experience many transitions, often in outside-of-school contexts such as when developing peer relationships, increasing mobility and independence, or moving towards post-secondary education and work. Between 0.65 and 2.5% of the world's population is diagnosed with autism spectrum disorder (ASD). Adolescents with ASD participate significantly less in age-specific living situations. Participation, defined by the World Health Organization as "involvement in a life situation," is embedded in environments such as with families, social clubs or in the community. Everywhere, an individual-environmental transaction occurs. An environmental focus can offer new perspectives to support participation for socially challenged persons, such as adolescents with ASD. This dissertation aims to elaborate on the role of environments in the participation of adolescents with ASD. Hopefully, the gained insight will benefit adolescents with ASD and improve their participation.

## CHAPTER 1

This chapter introduces the topic under research. It characterizes ASD as a lifelong condition, presents global prevalence rates, gives an overview of the poor longitudinal outcomes in major life areas observed in individuals with ASD, and outlines the economic consequences for societies. Next, it argues for a focus on adolescents with ASD. It describes their low participation rates, referring to a classification defined by the WHO in the International Classification of Functioning, Disability, and Health (ICF). By using ICF, supporting and hindering environments for the participation of adolescents with ASD are introduced and explained in the context of the role of parents and families within their immediate social environments.

A problem summary and the presentation of the research gaps follows. This leads to the main aim of deepening our understanding of the role of environments as supportive or hindering to the participation of adolescents with autism spectrum disorder. Two subsequent research questions guided the whole thesis:

1. What is the role of environments as supportive or hindering to the participation of adolescents with ASD as described in the literature and by adolescents themselves?

2. How do parents of adolescents with ASD perceive and describe the role of environments as supportive or hindering to the participation of these youth?

The chapter ends with the presentation of the context of the empirical parts of the study, which is Switzerland, and an overview of the following chapters.

## CHAPTER 2

This chapter contains a scoping review aiming to map the existing literature between 2001 and 2018 on supporting and hindering environments for the target group. Sources of scientific evidence were searched in 4 databases. Inclusion criteria were the perspectives of adolescents with ASD, families, or peers, participation in a natural context, and a clear connection between the environment and participation. The review covered scientific publications and identified 5528 articles. After a rigorous 5-step-selection procedure, 31 studies were thematically analyzed, and stakeholders validated the results.

Two sections presented the results: (1) a descriptive summary and (2) a narrative summary with three main themes and ten subthemes. *'Providing security'* showed how parental, physical, and informative environments have either a securing or intimidating effect on adolescents' participation. *'Helping to connect'* delineated how environments like peers and friends, services and staff, family, and attitudes support or hinder social relationships or social activities. *'Tension in participation'* summarized ambiguities regarding the participation of adolescents with ASDs, including topics such as isolation or solitary participation, involvement in disability-related groups, and the dilemma of normalcy and difference.

The scoping review found a complex interrelation between the participation of adolescents with ASD and their environment. These adolescents have a strong desire for positive peer relationship experiences. Security and connection, the most important environmental aspects, represent meaningful, subjectively relevant, and feasible aspects of how the environment can shape participation. This research widens the field regarding working with adolescents with ASD, as it directs attention towards the responsibility of the environment regarding participation.

## CHAPTER 3

This chapter describes a study which aimed to understand how and why participants perceive aspects of their environment as facilitators or barriers to their participation outside of home and school in the region of Zurich. Six male adolescents participated in in-depth interviews and took photos during their participation activities. Transcribed interviews and photos were analyzed. Their participation turned out to take place in a variety of areas and to be performed regularly and consistently. The favorite activity among the participants was using public transport. Interestingly, all participants perceived participation as a social act, even when they were solitary activities like attending libraries or hiking.

Results revealed two main themes and 10 subthemes that seemed necessary to facilitate participation: *‘Environmental pre-requisites to attend participation’* were imperative to begin participating. These comprised (1) the company of trusted persons, (2) the presence of a nudging drive (with elements of obligation, habituation, interest, and motivation), (3) the provision of knowledge and information, (4) the presence of good vibes, and (5) the design of the physical environment. The second main theme, *‘social interchange and engagement’* was related to the occurrence of social reciprocity when adolescents with ASD interacted with people other than their trusted persons during social activities. Three subthemes described how actual involvement could be supported: (1) being approached, (2) becoming a group member, and (3) being acknowledged and gently guided. The results of this study confirmed various themes of the scoping review. The findings highlighted the influence of trusted persons on adolescents with ASD and the need to extend the support network for these adolescents to other individuals, services, and society to encourage their participation in activities.

## CHAPTER 4

This chapter presents research aiming to translate and cross-culturally adapt the Participation and Environment Measure- Child and Youth (PEM-CY) into German in a way that culturally represented the PEM-CY constructs of *‘participation’* and *‘environment’* in Switzerland, Germany, and Austria. Colleagues and the developers followed adapted cultural equivalence guidelines. Fifteen parents of children and adolescents with disabilities from these three countries participated in three rounds of

think-aloud interviews. Data were analyzed by content analysis using semantic, idiomatic, experiential, and conceptual equivalence.

Results showed adaptations mainly focused on experiential and conceptual equivalence with conceptual equivalence being the most challenging to achieve. Examples of experiential equivalence included adapting the examples of activities in the PEM-CY to reflect those typical in German-speaking countries. Conceptual equivalence mainly addressed aspects of “involvement” and “environment” and was reached through adaptations such as enhanced instructions and structures and additional definitions.

To conclude, the study presents a culturally adapted version of PEM-CY (German) available for research, practice, and further validation.

## CHAPTER 5

This chapter presents a study that aimed to describe parental perspectives on the participation patterns of children and adolescents with ASD at home, at school, and in the community of children as well as parental desires to change these patterns. 60 parents of children and 55 parents of adolescents with ASD in the German-speaking part of Switzerland participated in this cross-sectional study. An online survey contained the PEM-CY(G) and demographic and health-related questions. Data were analyzed descriptively and thematically for both age groups, which did not differ significantly ( $p = 0.5$ ) regarding the type of residence and parents' education level. The manifestation of autistic symptoms indicated that both groups represented a less severe sample of the autistic spectrum.

Results showed different participation patterns in all settings and both age groups. Both participated most often at home, but high percentages of parents desired changes, such as in *'getting together with others'* and *'household chores'* or *'personal care management'*. The younger group was more involved at home than the older group. The school participation of both groups varied greatly, and parents' desires for change referred frequently to *'getting together with other children of class'*. Community participation in both age groups was low, and in half of the activities it was non-existent. Parents primarily desired more participation frequency in *'getting together with other peers in the community'*, and *'structured and unstructured physical*

*activities*’. Overall, parents of adolescents with ASD expressed a stronger desire for change in all three settings than parents of children with ASD. Parents of both age groups wanted higher participation frequency and involvement for all activities, with two exceptions: *‘gaming’* and *‘watching films.’* To conclude, this research informed the scientific community and social, health, and community service providers about how to reshape their programs to meet parental needs and supports for the participation of children and adolescents with ASD.

## CHAPTER 6

This chapter aimed to describe parental perspectives on environmental supports and barriers, combined with parental contextual strategies in three settings (home, school, community). Data collected in the same cross-sectional study as described in chapter 5 was used and analyzed similarly quantitatively and qualitatively. Results revealed that half of the parents in Switzerland perceived more environmental supports than barriers for their children’s participation as assessed by the PEM-CY (G). Supports included aspects such as *‘services,’ ‘information,’ ‘time,’* and *‘money.’* In contrast, environmental aspects such as *‘physical layout,’ ‘sensory quality,’ ‘demands of activities,’ ‘relationships,’* or *‘attitudes’* were seen as significant barriers to participation. In both age groups, *‘sensory aspects’* and *‘social demands of activities’* were the greatest barriers in all three settings. This was explicitly the case in the community setting, where environments are more flexible and less predictable. The other half of parents did not describe environmental aspects clearly as barriers or as supports for their children’s participation.

Parental contextual strategies comprised 41% of all comments regarding *‘people,’* thus being a social aspect. Another 37% of strategies were associated with *‘activities.’* *‘Time,’ ‘objects,’* and *‘places’* were far less mentioned but were as well. Most parental strategies were used in all settings and were similar across both age groups. To conclude, despite parents seeing more supports than barriers in their children’s environments, barriers were described as less tangible and less changeable by parents. Parental perspectives on participation and their contextual strategies need to be considered in environment-based interventions to support the social participation of children and adolescents with ASD. This can simultaneously reduce caretaking-related strain in parents of children and adolescents with ASD.

## CHAPTER 7

This chapter first provides a summary of the most relevant and interesting discussion points obtained from the literature review and the four empirical studies to answer the research question. Seven important environments for the participation of adolescents with ASD were identified. Then, the chapter reflects on the theoretical lenses used throughout the dissertation and the understanding gained about the participation of adolescents with ASD. Next, the seven identified environments which represent our insight about the role of the environment for their participation are discussed. Methodological considerations follow before the chapter ends with recommendations

## CHAPTER 9

This chapter presents in layman's terms the scientific impact of the research and its achieved and anticipated relevance for practice, teaching, service implementations, and society to support the participation of adolescents with ASD and their families.

# ZUSAMMENFASSUNG

Adoleszenz ist eine Zeit körperlicher Anpassungen, die auch mit Rollenwechseln innerhalb von Familie und Gesellschaft einhergeht. Jugendliche erleben viele Übergänge, oft in außerschulischen Kontexten, z.B. wenn sie Beziehungen zu Gleichaltrigen aufbauen, ihre Mobilität und Unabhängigkeit erweitern oder sich in Richtung postsekundärer Bildung und Arbeit bewegen. Bei 0,65 bis 2,5% der Weltbevölkerung wird eine Autismus-Spektrum-Störung (ASS) diagnostiziert. Jugendliche mit ASS nehmen deutlich weniger an altersspezifischen Lebenssituationen teil. Partizipation oder Teilhabe<sup>1</sup>, definiert von der Weltgesundheitsorganisation als „*Einbezogenheit in eine Lebenssituation*“, ist immer in einer Umwelt eingebettet und oft mit einem typischen Umfeld wie Familie, Verein oder im öffentlichen Raum verbunden. Überall dort findet eine Personen-Umwelt-Transaktion statt. Den Blick auf die Umwelt und das Umfeld zu legen kann neue Perspektiven auf die Unterstützung der Teilhabe von sozial benachteiligten Personen, wie z. B. Jugendliche mit ASS ermöglichen. Die vorliegende Dissertation ergründet die Rolle der Umwelt und des Umfeldes für der Partizipation (Teilhabe) von Jugendlichen mit ASS. Sie ist mit der Hoffnung verbunden, dass die gewonnenen Erkenntnisse Jugendlichen mit ASS zugutekommen und deren Partizipation verbessern.

## KAPITEL 1

In diesem einführenden Kapitel wird zunächst der Begriff der Autismus-Spektrum-Störung (ASS) über die gesamte Lebensspanne charakterisiert. Danach stellt das Kapitel globale Prävalenzraten von ASS dar, gibt einen Überblick über die derzeit erfassten und oft als enttäuschend eingeschätzten Langzeitverläufe in wichtigen Lebensbereichen (wie Arbeit, Wohnen und Beziehungen) und skizziert die daraus resultierenden wirtschaftlichen Folgen für die Gesellschaft. Es folgt eine Begründung, warum der Fokus der Arbeit auf Jugendlichen mit ASS liegt. Auf dem Hintergrund der Internationalen Klassifikation der Funktionsfähigkeit, Behinderung und Gesundheit (ICF) der WHO beschreibt das Kapitel die geringe Teilhabe von Jugendlichen mit ASS in verschiedenen Lebensbereichen. Ebenfalls basierend auf der ICF werden unterstützende und behindernde Umweltfaktoren für deren Teilhabe dargelegt. Die

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<sup>1</sup> In der vorliegenden Arbeit werden die Begriffe «Partizipation» und «Teilhabe» synonym und die Begriffe «Umwelt» und «Umfeld» ergänzend verwendet.



Rolle der Eltern und Familien im unmittelbaren sozialen Umfeld von Jugendlichen mit ASS wird dabei hervorgehoben.

Es folgt eine Problemzusammenfassung und die Darstellung der Forschungslücken, aus denen sich das Hauptziel der Arbeit ableitet: ein vertieftes Verständnis der unterstützenden und /oder hinderlichen Rolle von Umwelt und Umwelt für die Teilhabe von Jugendlichen mit ASS zu erlangen. Zwei aufeinander aufbauende Forschungsfragen leiteten die gesamte Arbeit:

1. Wie beschreiben die bestehende Forschungsliteratur und Jugendliche mit ASS selbst die Rolle der Umwelt und des Umfeldes als unterstützend oder hinderlich für die Teilhabe von Jugendlichen mit ASS?
2. Wie nehmen Eltern von Jugendlichen mit ASS die Rolle der Umwelt und des Umfeldes für die Teilhabe der Jugendlichen mit ASS als unterstützend oder hinderlich wahr und wie beschreiben sie diese?

Das Kapitel endet mit der Darstellung des Schweizer Kontextes, in dem die empirischen Teile der Dissertation stattfanden und gibt einem Überblick über die folgenden Kapitel.

## KAPITEL 2

Dieses Kapitel beschreibt einen Scoping-Review, dessen Ziel es war, vorhandene Literatur zwischen 2001 und 2018 zu unterstützenden und hinderlichen Umwelt und Umfeldfaktoren für die Zielgruppe abzubilden. Quellen wissenschaftlicher Evidenz wurden in 4 Datenbanken gesucht. Einschlusskriterien waren die Perspektiven von Jugendlichen mit ASS, Familien oder Gleichaltrigen, die Teilhabe in einem natürlichen Umfeld und ein klarer Zusammenhang zwischen Umwelt und Partizipation. Die Suche identifizierte 5528 wissenschaftlich Artikel. Nach einem stringenten 5-Stufen-Auswahlverfahren wurden 31 Studien thematisch analysiert und die Ergebnisse von Stakeholdern validiert.

Die Präsentation der Ergebnisse erfolgte in zwei Teilen: (1) einer quantitativ-deskriptiven Zusammenfassung und (2) einer narrativen Zusammenfassung mit drei Hauptthemen und zehn Unterthemen. Das Thema «*Sicherheit vermitteln*» beschreibt wie elterliche, physische und informative Umwelten entweder eine sichernde oder eine einschüchternde Wirkung auf die Teilhabe von Jugendlichen haben. Das zweite Thema «*Hilfe zur sozialen Verbundenheit*» zeigt auf, wie das Umfeld, etwa Gleichaltrige und

Freunde, Institutionen und Dienstleistungserbringende, Familie und auch generell Einstellungen von Personen, soziale Beziehungen oder soziale Aktivitäten für Jugendliche mit ASS unterstützt oder erschwert. *«Spannungsfelder von Teilhabe»* fasst Unklarheiten bezüglich der Teilhabe von Jugendlichen mit ASS zusammen. Darunter fallen Themen wie Isolation oder singuläre Teilhabe, Einbindung in Behindertengruppen und das Dilemma zwischen Normalität und Andersartigkeit.

Der Scopingreview zeigte eine komplexe Wechselbeziehung zwischen der Partizipation von Jugendlichen mit ASS und ihrem Umfeld. Diese Jugendlichen wünschen sich positiven Erfahrungen in den Beziehungen zu Gleichaltrigen, Sicherheit und Verbundenheit. Die wichtigsten Umwelt - und Umfeldfaktoren stellen sinnvolle, subjektiv relevante und realisierbare Aspekte dar, die für die Partizipation verwendet werden können. Die vorliegende Forschung erweitert die Möglichkeiten, mit Jugendlichen mit ASS zu arbeiten, da sie die Aufmerksamkeit auf die Verantwortung der Umwelt und des Umfeldes für die Partizipation lenkt.

### KAPITEL 3

Das Ziel der im Kapitel 3 dargestellten Studie war es vertiefter zu verstehen, wie und warum die Jugendliche mit ASS Aspekte ihrer Umwelt und ihres Umfeldes als unterstützend oder behindernd für ihre Teilnahme ausserhalb von Zuhause und der Schule wahrnahmen. An der Fallstudie nahmen sechs männlichen Jugendlichen mit ASS aus der Region Zürich teil. Wir analysierten vertiefende Interviews und Fotos, die die Teilnehmenden während den Aktivitäten, an denen sie teilnahmen, aufnahmen. Es stellte sich heraus, dass Partizipation in einer Vielzahl von Bereichen stattfand und regelmässig und kontinuierlich durchgeführt wurde. Die Lieblingsaktivität der Teilnehmer war die Nutzung öffentlicher Verkehrsmittel. Interessanterweise empfanden alle Teilhabe als einen sozialen Akt, selbst wenn es sich um Aktivitäten wie Bibliotheksbesuche oder Wanderungen handelte, die die Jugendlichen allein durchführten.

Die Ergebnisse stellen zwei notwendige Hauptthemen mit 10 Unterthemen dar, die Teilhabe der Jugendlichen mit ASS erleichterten: Zuerst waren *«Voraussetzungen des Umfeldes um anwesend zu sein»* zwingend erforderlich, um partizipative bei einer Aktivität einzusteigen. Dazu gehörten (1) Begleitung von Vertrauenspersonen, (2) Antrieb (mit Elementen von Verpflichtung, Gewöhnung, Interesse und Motivation), (3)

Verfügbarkeit von Wissen und Informationen, (4) insgesamt eine gute, freundliche Stimmung und (5) Designaspekte der physischen Umwelt. Das zweite Hauptthema, *«sozialer Austausch und Engagement»*, bezog sich auf das Vorhandensein von sozialer Gegenseitigkeit, wenn Jugendliche mit ASS bei sozialen Aktivitäten mit anderen als ihren Vertrauenspersonen interagierten. Drei Unterthemen beschrieben, wie diese aktive Beteiligung unterstützt werden kann: die Jugendlichen möchten (1) angesprochen werden, (2) ein Gruppenmitglied werden und (3) anerkannt und sanft gelenkt werden. Die Ergebnisse bestätigten verschiedene Themen aus der Scoping-Review. Sie unterstreicht den Einfluss von Vertrauenspersonen bei Jugendlichen mit ASS und die Notwendigkeit, ein Unterstützungsnetzwerk auf anderen Personen, Dienstleistungserbringenden und der Gesellschaft auszudehnen, um ihre Partizipation zu fördern.

## KAPITEL 4

Dieses Kapitel stellt eine Forschungsarbeit vor, deren Ziel es war, das *«Measurment of Environment and Participation - Child and Youth»* ins Deutsche zu übersetzen und transkulturell so anzupassen, dass die PEM-CY-Konstrukte „Partizipation“ und „Umwelt/Umfeld“ in Deutschland, der Schweiz und Österreich für Kinder und Jugendliche kulturell repräsentiert werden. Eine Gruppe Berufspersonen folgten gemeinsam mit den Entwickelnden aus Kanada angepassten kulturellen Äquivalenzrichtlinien. Fünfzehn Eltern von Kindern und Jugendlichen mit Beeinträchtigungen aus den drei deutschsprachigen Ländern nahmen an insgesamt drei Gesprächsrunden teil, in denen die *«Think-Aloud»* Technik angewendet wurde. Die Daten wurden mit einer Inhaltsanalyse unter Verwendung semantischer, idiomatischer, erfahrungsbezogener und konzeptioneller Äquivalenzen analysiert.

Die Ergebnisse zeigten Anpassungen, die sich hauptsächlich auf erfahrungsbezogene und konzeptionelle Äquivalenz konzentrierten, wobei die konzeptionelle Äquivalenz am schwierigsten zu erreichen war. Beispiele für erfahrungsbezogene Äquivalenz waren die Anpassung der Aktivitätsbeispiele des PEM-CY, um die im deutschsprachigen Raum typischen Aktivitäten abzubilden. Die konzeptionelle Äquivalenz befasste sich hauptsächlich mit den Aspekten *«Engagement»* und *«Umwelt/Umfeld»* und wurde durch Anpassungen wie verbesserte Anweisungen und Strukturen und zusätzlichen Definitionen erreicht. Nach Abschluss der Arbeit ist eine kulturell angepasste Version

des PEM-CY (G) vorhanden, die nun für Forschung, Praxis und zur weiteren Validierung zur Verfügung steht.

## KAPITEL 5

Dieses Kapitel stellt eine Studie dar, deren Ziel es war, die Partizipationsmuster von in der Schweiz lebenden Kindern und Jugendlichen mit ASS zu Hause, in der Schule und in der Gesellschaft aus elterlicher Perspektive darzustellen. Zusätzlich beschrieben Eltern, welche Veränderungswünsche sie sich für diese Partizipationsmuster wünschten. An der Querschnittsstudie nahmen 60 Eltern von Kindern mit ASS und 55 Eltern von Jugendlichen mit ASS in der deutschsprachigen Schweiz teil. Eine Online-Umfrage beinhaltete den PEM-CY(G) sowie demografische und gesundheitsbezogene Fragen. Die Daten wurden deskriptiv und thematisch für beide Altersgruppen analysiert, die sich hinsichtlich der Wohnform und des Bildungsniveaus der Eltern nicht signifikant ( $p = 0,5$ ) voneinander unterschieden. Die Verteilung autistischer Symptome deutete darauf hin, dass beide Gruppen eine weniger schwere Stichprobe innerhalb des ganzen autistischen Spektrums repräsentierten.

Die Ergebnisse zeigten unterschiedliche Partizipationsmuster in allen drei Kontexten und zwischen den Altersgruppen. Beide Altersgruppen beteiligten sich am häufigsten zu Hause, jedoch war trotzdem der Anteil der Eltern, die sich Veränderungen zu Hause wünschten, hoch. Veränderungswünsche betrafen beispielsweise Items wie *«Mit anderen Zeit verbringen»*, *«Arbeiten im Haushalt»* oder *«Körperpflege»*. Insgesamt waren die jüngeren Kinder zu Hause stärker engagiert als die Jugendlichen. Die Schulbeteiligung beider Gruppen war sehr unterschiedlich und Veränderungswünsche der Eltern bezogen sich häufig auf *«Zusammensein mit Gleichaltrigen im Klassenzimmer»*. Gesellschaftliche Partizipation war in beiden Altersgruppen selten und bei der Hälfte der Aktivitäten inexistent. Eltern wünschten sich vor allem häufigere Beteiligung beim *«Zusammensein mit anderen Kindern und Jugendlichen»* und bei *«strukturierten und unstrukturierten körperlichen Aktivitäten»*. Insgesamt äusserten Eltern von Jugendlichen in allen drei Kontexten mehr Veränderungswünsche als Eltern von Kindern. Die Richtung der Veränderungswünsche war bei fast allen Aktivitäten hin zu *«vermehrte»* und *«engagierter»*. Es gab dabei nur zwei Ausnahmen: *«Computerspiele (Gamen)»* und *«Filme schauen»*.

Diese Arbeit informiert Wissenschaft generell und Dienstleistungsanbietende in den Bereichen Soziales, Gesundheit oder Erziehung spezifisch darüber, wie sie angebotene Programme gestaltet oder neu entwickeln können, um den Wünschen der Eltern von Kindern und Jugendlichen mit ASS mehr entgegenzukommen und dadurch die Teilhabe dieser Kinder und Jugendlichen zu unterstützen.

## KAPITEL 6

Ziel der in diesem Kapitel beschriebenen Studie war darzustellen, wie Eltern von in der Schweiz lebenden Kindern und Jugendlichen mit ASS unterstützende und hemmende Umwelt- und Umfeldaspekte für die Partizipation ihrer Kinder mit ASS in drei Kontexten (Zuhause, in der Schule und in der Gesellschaft) einschätzten. Zusätzlich beschrieben Eltern ihre eigenen umweltbezogenen Strategien, um die Partizipation ihrer Kinder zu unterstützen. Für diese Studie wurden Daten aus der im 5. Kapitel beschriebenen Querschnittsstudie verwendet und ähnlich quantitativ und qualitativ analysiert. Die Ergebnisse zeigten, dass die Hälfte der Eltern in der deutschsprachigen Schweiz laut PEM-CY (G) mehr Unterstützung als Hindernisse durch die Umwelt und das Umfeld für die Teilhabe ihrer Kinder erfuhren. Aspekte wie *«Dienstleistungen»*, *«Informationen»*, *«Zeit»* und *«Geld»* wurden als unterstützend eingeschätzt. Im Gegensatz dazu wurden Umweltaspekte wie *«Raumaufteilung, der Platz oder architektonisch Aspekte»*, *«sensorische Faktoren»*, und Umfeldaspekte wie *«Anforderungen an Aktivitäten»*, *«Beziehungen»* oder *«Einstellungen»* als erhebliche Hindernisse für die Teilhabe angesehen. In beiden Alterskategorien waren *«sensorische Aspekte»* und *«soziale Anforderungen an Aktivitäten»* die größten Barrieren in allen drei Kontexten. Dies war ausdrücklich im gesellschaftlichen Kontext der Fall, wo Umwelt und Umfeld flexibler und damit weniger vorhersehbar sind. Für die zweite Hälfte der Eltern waren die Umweltaspekte nicht eindeutig als unterstützend oder hinderlich für die Partizipation ihrer Kinder einzuordnen.

Bei den umweltbezogenen Strategien der Eltern standen 41% aller erhaltenen Kommentare in Verbindung zum *«Menschen»* und waren somit sozialer Natur. Weitere 37% der Strategien wurden mit *«Aktivitäten»* in Verbindung gebracht. Strategien in Verbindung mit *«Zeit»*, *«Objekten»* und *«Orten»* waren zwar vorhanden, wurden aber deutlich weniger häufig erwähnt. Die meisten elterlichen Strategien wurden in allen Kontexten verwendet und waren in beiden Altersgruppen ähnlich.

Abschliessend lässt sich sagen, dass obwohl Eltern in der Umwelt und dem Umfeld ihrer Kinder mehr Unterstützung als Hindernisse wahrnahmen. Eltern beschrieben die Hindernisse als weniger greifbar und damit auch weniger veränderbar. Die Perspektive von Eltern und deren umweltbezogenen Strategien zur Unterstützung der Partizipation ihrer Kinder mit ASS müssen in umweltbasierten Interventionen berücksichtigt werden, um die soziale Partizipation von Kindern und Jugendlichen mit ASS zu unterstützen. Dies kann gleichzeitig die betreuungsbedingte Belastung von Eltern von Kindern und Jugendlichen mit ASS reduzieren.

## KAPITEL 7

Dieses als Diskussion bezeichnete Kapitel fasst zunächst wichtigste und interessanteste Ergebnisse des Literaturreviews und der vier empirischen Studien zur Beantwortung der beiden Forschungsfragen zusammen. Wichtig für die Partizipation von Jugendlichen mit ASS sind gemäss der vorliegenden Forschung sieben unterschiedliche Umfelder. Anschliessend werden die verwendeten theoretischen «Blickwinkel» der Dissertation und vertiefende Einsichten zur Partizipation von Jugendlichen mit ASS reflektiert. Die Rolle der Umwelt und des Umfeldes für die Partizipation der Jugendlichen mit ASS wird entlang entlang der sieben herausgearbeiteten Umfelder diskutiert. Methodologische Betrachtungen folgen und das Kapitel endet mit Empfehlungen.

## KAPITEL 9

Dieses Kapitel stellt in allgemeinverständlicher Sprache die wissenschaftliche Wirkung der vorliegenden Forschung und ihre erreichte und erwartete Relevanz für Praxis, Lehre, Dienstleistungen und Dienstleistende und für die allgemeine Gesellschaft dar, um die Teilhabe von Jugendlichen mit ASS und deren Familien zu unterstützen.



# CHAPTER 9

Impact







## IMPACT

*This chapter presents in layman's terms the aims, the research questions, and the results of the dissertation, followed by the impact this dissertation will have on different stakeholders: the scientific community, fields of practice, education of professionals, service delivery and provision, society in general, and adolescents on the autism spectrum and their parents and families.*



Foto from Marc, permission to publish perceived

### Case 1: Marc (22) university student, concert visitor, boyfriend

Two years later, Marc is still in a partnership with his girlfriend. Together, they have managed to attend many more concerts and other different activities. Recently, they are thinking about jointly leaving Switzerland. During his master's study, Marc was offered an attractive post abroad. He knows that, accompanied by his girlfriend, he feels supported in pursuing new adventures.



retrieved from the website of the cantonal fishing club Zürich <https://www.fkz.ch>

### Case 2: Phillip (17) member of the local fishing club

Two years later, Phillip is still a member of the fishing club. He became part of the organization team of his club. This small team organizes a fish market twice a year, where they serve fish and chips to fundraise for the club. Phillip loves to serve customers; he made the pricing lists and is responsible for the stocks during market time. His team acknowledges his reliability and steadiness.



retrieved from <https://de.vecteezy.com/vektorkunst/2919245>

### Case 3: Luc (17) apprentice, taekwondo practitioner

Two years later, Luc still attends taekwondo training. Prompted by his trainer, he applied to join the para-olympic competitions. He regularly attends international competitions in taekwondo. While traveling and during competitions, he is accompanied by his trainers and other staff who support him. Peers in his club take turns in being part of his accompanying staff.

They are proud of Luc.

Marc, Phillip, and Luc experience participation because of the support of their friends, parents, or an engaged trainer. This helps them to increase their attendance and involvement. They can develop their capacities and talents further and experiences fun and acceptance. These are examples for supportive environment. The World Health Organization<sup>1,2</sup> writes that participation is “involvement in a life situation”, adolescents of this study described it with “daring to join and proudly experiencing joyful activities”.

## INTRODUCTION TO THE TOPIC AND RESEARCH QUESTION

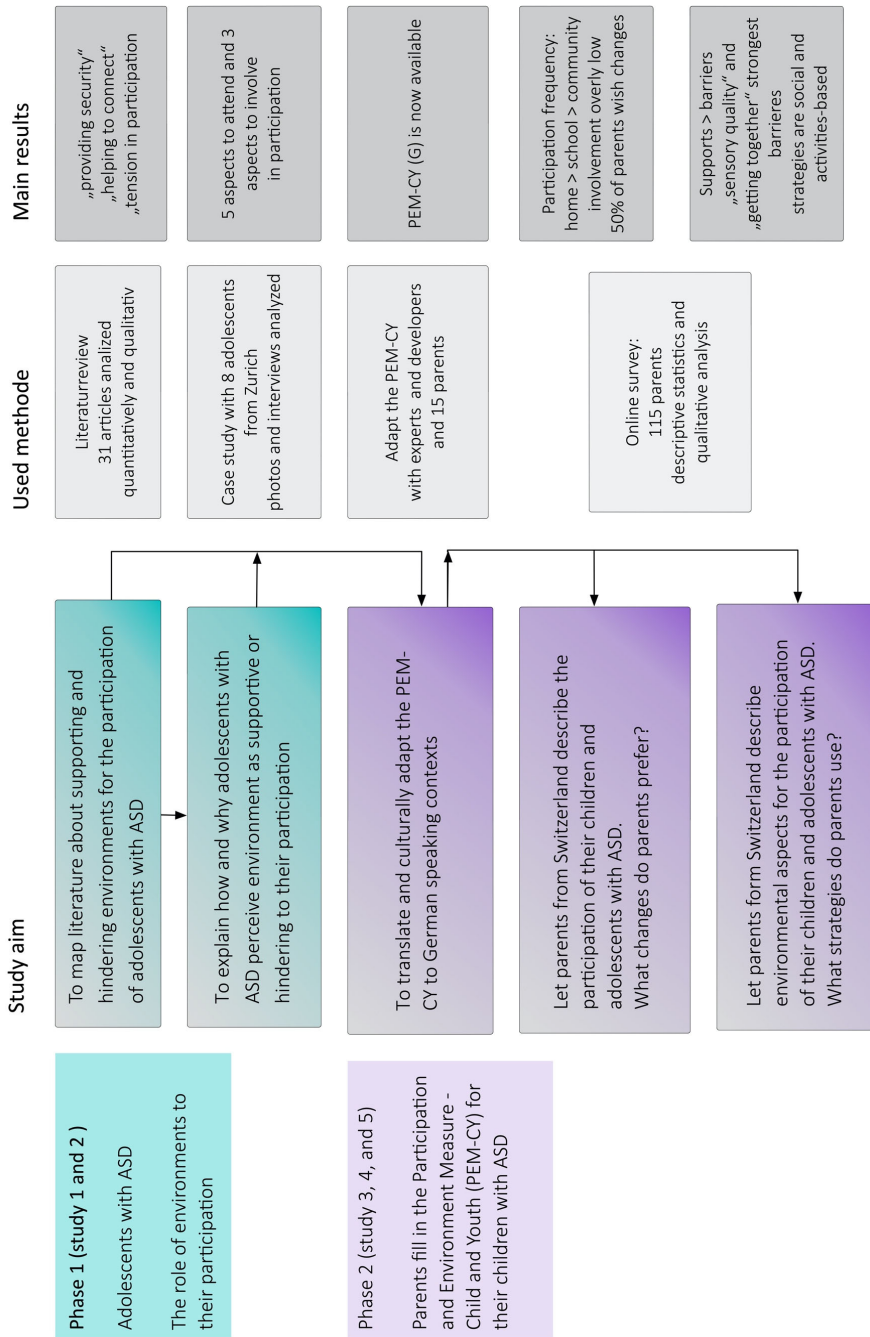
Adolescence is a period of physical adjustment and role changes within the family and society. Adolescents experience many transitions, often in outside-of-school contexts such as when developing peer relationships, increasing mobility, achieving independence, or moving towards post-secondary education or work. Between 0.65 and 2.5% of the world's population is diagnosed with autism spectrum disorder (ASD).<sup>3,4</sup> Adolescents with ASD participate significantly less in age-specific living situations<sup>5,6,7,8,9,10,11</sup> which has negative consequences for adulthood. Participation is embedded in environments such as family life, the physical environment, social groups, school, leisure activities, or in the community. Thus, in each of these life situations, an interaction between the individual person and the environment occurs. Focusing on environments offers a new perspective on supporting participation for socially challenged and vulnerable persons, such as adolescents with ASD.

This research aimed to deepen our understanding of the role of environments as supportive or hindering to the participation of adolescents with autism spectrum disorder. Two subsequent research questions guided the entire thesis:

1. What is the role of environments as supportive or hindering to the participation of adolescents with ASD as described in the literature and by adolescents themselves?
2. How do parents of adolescents with ASD perceive and describe the role of environments as being supportive or hindering to the participation of these youth?

## OVERVIEW OF THE DISSERTATION AND SUMMARY OF RESULTS

Within this dissertation, we conducted five consecutive studies (2 phases). Figure 9.1. provides an overview of each study's aim in layman's terms, a summary of the methods used and the main results. The empirical parts of the dissertation were performed in the German-speaking part of Switzerland.

**Figure 9.1** Overview of the dissertation with aims, methods used, and main results...

The dissertation deepened our understanding of the role of environments and contexts on the participation of adolescents with ASD. Their participation is less normative, and solitary and social activities are perceived as a kind of participation. Results highlight the importance of the parental and family environment and adolescents' need for company during participation. They further point to the special role that information and knowledge play for adolescents with ASD, the effect of physical aspects of the environment, and adolescents' need for motivation and nudges to connect and engage socially. Combatting negative attitudes is another important characteristic of an engaged, active, and supportive environment. The main role of environments is to make adolescents feel secure and help them to connect. As such, supportive environments seem more important for the participation of adolescents than simply removing barriers.

## IMPACT ON THE SCIENTIFIC COMMUNITY

First, this dissertation provided new insight into environmental supports and barriers to the participation of adolescents with ASD between 12 and 21 years of age and concretely presented seven essential environments. By illuminating the role of the environment, this dissertation contributes to a possible shift from a perspective that focused on the functional deficits of these adolescents to one focusing on environmental supports and barriers. The timing is exactly right, as this shift has already taken place regarding other childhood disabilities and has resulted in new and effective environmental-based interventions for these children.<sup>12,13</sup> In the field of ASD, this is yet to come, but this research provided a basis for future interventions and innovation. Published as open access, the literature review<sup>14</sup> received over 7800 views with 50% downloads in three years, and as of this writing, it has been cited between 27 (PLOS) or 38 (Google) times. It influenced, for example, research about the best environmental neighborhoods for supporting the sports participation of adolescents with ASD,<sup>15</sup> as well as research examining the connection between parental attitudes and participation in youth with ASD.<sup>16</sup>

Second, it provides insight into the participation of adolescents with ASD. Novel aspects include describing their own views on supports and barriers in the community.<sup>17</sup> Specifically, pre-requisites for participation attendance and support for participation involvement have never previously been described by adolescents with ASD

themselves. This research further adds to growing evidence that attendance and involvement/engagement are two subdimensions of participation.<sup>18</sup>

Third, this research influences scientific discourse on participation by adding reflections on ‘tensions in participation.’<sup>14</sup> It ascertains that participation must be subjectively defined by the participating individuals<sup>19,20</sup> and brings more qualifiers of participation into the discussion (e.g. when does an adolescent with ASD feel secure and informed enough to participate). For adolescents with ASD, solitary activities are perceived as participation and are even seen as social acts.<sup>14,17</sup> The work also raises questions about whether participation in diagnostic-related groups should be considered as participation or as a sign of segregation and exclusion.<sup>14</sup> Normative participation was further examined during the cultural adaptation of an assessment.<sup>21</sup> Specifically, parents of children with a severe disability reflected on the demands or possible adaptations that accompany the concept of participation. Looking at new output in the participation literature, some of these aspects are already cited in theoretical papers.<sup>18,19</sup> The ‘tensions in participation’ will provide further new areas of participation related research.

Finally, this research increases our understanding of the transactional relationship between participation and the environment. Both reciprocally influence each other. Although this connection is widely acknowledged, it is novel how this dissertation combines the different theoretical lenses of ‘participation’ and ‘environment’, which mutually supplement each other. Hence, the ICF definition of ‘participation’ could be more specific if it identified social and occupational roles and the subdimensions of ‘attendance’ and ‘involvement.’ The ICF definition of ‘environment’ was qualitatively enriched via the ‘restorative person model’<sup>22,23</sup> (stressing informative, restoring environments) plus the ‘activity setting perspective’<sup>24</sup> which clearly differentiate between ‘environment,’ ‘setting’ and ‘context’ for any activity and participation. This might impact a new field in environmental research, as experienced in a closer collaboration between the author and an environmental psychologist, which resulted in a recently submitted publication on workplace adjustments for neurodiverse persons.<sup>25</sup>

## IMPACT ON PROFESSIONAL PRACTICE

Practice comprises all persons who directly work with adolescents with ASD as professionals. These are occupational therapists, speech pathologists, psychologists, physicians, teachers, leisure instructors or vocational counselors. Together they create the professional social-practice environment for adolescents with ASD.

The dissertation takes a goal-directed perspective: the goal is participation, extended here with *“being engaged in and/or performing meaningful activities in occupational and social roles.”* It informs professionals that 50% of parents from Switzerland wished to increase participation attendance and involvement for their children with ASD.<sup>26</sup> To achieve this, the strategies that are addressed in the seven subthemes within ‘providing security’ and ‘helping to connect socially’<sup>14</sup> can be concretely implemented by practitioners. They focus on changes to the environment instead of changes to the person’s behavior. Next, ‘environmental pre-requisites to attend activities’<sup>17</sup> provide concrete strategies for how to support the participation of adolescents with ASD outside of school and the home. Community training with targets such as buying groceries, using public transport, asking people for help, joining sports or clubs, or communicating with peers are applicable. Company can be provided by therapists, parents, family members, siblings, or trusted peers. Further, addressing nudges and drive as well as the informational needs of adolescents with ASD are novel aspects that help us understand how to collaborate in an environmentally focused way with adolescents with ASD.

Various articles, posters, and interviews have been produced to inform both Swiss<sup>27</sup> and international occupational therapists<sup>28,29</sup> and other professionals (such as rehabilitation specialists,<sup>30</sup> psychologists,<sup>31</sup> special needs teachers,<sup>32</sup> and the public health sector<sup>33</sup>) about these “tools.” Further, practitioners of all disciplines can now use the German version of the PEM-CY to assess participation and environments jointly for children and adolescents.

As a professional practitioner and entrepreneur myself, this environmental focus has enriched my occupational therapy practice with adolescents with ASD, my counseling to parents, and my supervision of colleagues and therapy teams.

## IMPACT ON EDUCATION OF PROFESSIONALS

As a lecturer at the Zurich University of Applied Sciences (in the department of health and at the institute of occupational therapy) my teaching activities and curriculum revision were strongly influenced by this dissertation. The environment has become more concrete in occupational therapy education, as have the needs of families. Environmentally focused interventions for adolescents with ASD became more central in my occupational therapy teaching. This was also reflected in the freely chosen topics that occupational therapy students chose for their bachelor's theses, which have been published and contributed to spreading professional understanding. Exemplary topics regarding connection with children and adolescents with ASD that I supervised were *'family mealtime habits,' 'toilet training,' 'sports participation,'<sup>32</sup> 'the use of assistant dogs to increase social participation,'* or *'women with ASD becoming mothers.'* Two of these theses won an annual prize from the Swiss Association of Occupational Therapists: *'Supporting transition to work in adolescents with ASD'*<sup>34</sup> and *'conditions of successful peer interventions in youth with ASD,'*<sup>35</sup> for which a publication is being prepared. Recently, topics such as *'the impact of Covid-19 pandemic on families with children on the autism spectrum,'* and *'the use of special interests to support participation of children with ASD,'* and *'activities of daily living to support independent living in young adults with ASD'* have also been a direct consequence of this dissertation.

Further impacts on education include the fact that the PEM-CY (G) is a newly offered assessment for students of occupational therapy. Finally, students of the entire health department could be inspired by seminars on qualitative research methods and lectures about publishing and collaborating with hard-to-reach research groups.

## IMPACT ON POLICY MAKERS, SERVICE PROVIDERS AND DELIVERY

Services for adolescents with ASD comprise agencies from the medical, educational, and social departments, all of which are regulated by policy makers and administrators in Switzerland. While some adhere to evidence-based practice, all adhere to economic reasoning. These agencies and the service delivery are both addressed directly or indirectly within this dissertation.

Participation and environment can for the first time be assessed together in children and adolescents in German-speaking countries<sup>21</sup> due to this dissertation. In



Switzerland, the PEM-CY (G) is already being used for the cerebral palsy registry and could be used for a further registry for autism spectrum disorder. PEM-CY(G) is also presented in an assessment database belonging to a German association of occupational therapists and further validation is planned in different research proposals. Combining assessment of the environment and participation is a powerful tool for interprofessional service planning and delivery. This is also reflected in a similar project that aims to culturally adapt a coherent assessment (Young Children Participation and Environment Measure) for small children.<sup>36</sup>

To increase professional adherence to guidelines, I translated the autism guidelines of the American Occupational Association into German. These have been edited and published, and they provide a sound evidence base for service delivery specifically in occupational therapy.<sup>37</sup> As a consequence of my autism specific publications, my expertise was nationally acknowledged and I was invited to attend a federal advisory committee of the Swiss government to deal with service security and service improvement for children and adolescents with ASD. The group prepared a report, which was later signed and published by the Swiss Federal Council.<sup>38</sup>

Due to the methodological expertise gained through this dissertation, I was able to join another research project launched in 2018 by the Swiss Federal Social Insurance Office (FSIO). We reviewed the literature on the evidence for early intensive treatment in young children with ASD, summarized the economic costs of caring for a child with ASD, and evaluated five pilot programs.<sup>39–41</sup> Our evaluation highlighted the importance of family-centered care and service-user involvement in general. It could be argued that supporting parents of children with ASD in daily care is from a societal perspective economically less burdensome due to increased workload and taxation. Based on this research, a structure for widening services has been built, resulting in seven new centers preparing for service delivery. Additionally, in November 2021, the FSIO changed its eligibility criteria for children with ASD for early intensive treatment.

To influence service provision and delivery in children and adolescents with ASD further, this study contributed to the outcome-focused quantitative data set. The presented data<sup>26,42</sup> is novel for Switzerland and informs health and social systems about the participation of children and adolescents on the autism spectrum, parental desires for change, and environmental barriers and support. Specifically, barriers for

participation indicates possible areas for refinement and improvement. The wished changes of home participation may particularly concern the occupational therapy and curative early education fields, as these services deliver home intervention. The non-participation of children and adolescents with ASD in Switzerland should concern public health officials, sports organizations, and vocational service providers for persons with ASD. Without experience in age-related community activities, adolescents and young adults with ASD cannot be included in the preferable first labor workforce or in any independent living situations. This dissertation highlights the importance of starting early, as adolescents with ASD need longer to adapt to new situations. Occupational therapy, social services, psychology, and voluntary services can step in to support parents and families, who in accordance with the UN convention on disability rights<sup>43</sup> are entitled to receive necessary services that contribute towards the equal enjoyment of persons with disabilities.

Finally, the collected data can be used for further longitudinal research in young persons with ASD in Switzerland.

## IMPACT ON GENERAL SOCIETY

According to the UN Disability Rights Convention, society needs to raise awareness regarding people with disabilities. For adolescents with ASD, this dissertation promotes a positive perception of adolescents with ASD and greater social awareness. Individuals and public institutions (such as museums, emergency departments, or administrations) can support adolescents with ASD through the aspects elaborated in this dissertation. Personally, I wish to contribute more actively to positive attitudes towards people with ASD, such as through the Swiss parents' association for ASD (autismus deutsche schweiz) and through posts on an online chatroom ([www.autismusforum.ch](http://www.autismusforum.ch)) in Switzerland.

For society, the scope of understanding of persons with ASD needs to be broadened as attitudes are still very much stereotyped. Analysis of newspapers during 2014 and 2017 for the case study<sup>17</sup> showed the limitations of public perceptions of autism: it is either idealized (indicated by newspaper features about extraordinary people with ASD and successful work stories about people with ASD in informatics) or as something strange and in need of a solution (indicated by features on the diagnostics of ASD and discussions about the causes of autism). This dissertation brings attention to the day-

to-day reality of living with ASD, and the needs of people with ASD and their families. It is important to present more successful participation stories of adolescents on the autism spectrum, such as in books or exhibitions. This dissertation shows that the successful participation of adolescents with ASD is a mutual achievement of adolescents themselves and their supporting environments.

## IMPACT ON ADOLESCENTS ON THE AUTISM SPECTRUM AND THEIR PARENTS AND FAMILIES

This research empowers adolescents with ASD and their families by giving them ideas about how to interact more within their environments and how to focus on environmental support strategies. Often, parents of children with ASD have lost their social support networks due to their family situation. But this can change. The research from this dissertation has been published in open access journals. According to PLOS metrics, 80% are non-professionals, indicating a huge interest from this population. The topics of this dissertation will be further elaborated on the already established website (<https://participation-autism.ch/>) which has recently gained 16% more regular visitors. Participation is one of the essences of life. Successful participation stories are desperately needed to change negative stereotypes about ASD. With an inventive and willingly social environment, much is possible. It is important to envision environmentally based solutions for meaningful participation. The author Peter Vermeulen from Belgium told the story of a boy with ASD who loved to hear glasses smash.<sup>44</sup> The more glasses were hidden from him, the more efforts he made to find and smash them. How could he possibly live a meaningful life? The community found a solution. Today, as an adult, he collects glass bottles in his community and recycles them. He is still joyful about each bottle he drops into the recycling container. This is an example of environmentally focused solutions rather than aiming primarily to change the functioning of a person with ASD.

After 2 years I followed Marc and his girlfriend, Phillip with his parents in the fish club and Luc in his taekwondo club up. To them participation is a process. They made progresses. When environments support participation, it is more likely that experiences, trust, and courage will enroll and result in more involvement and enriching participation experiences.

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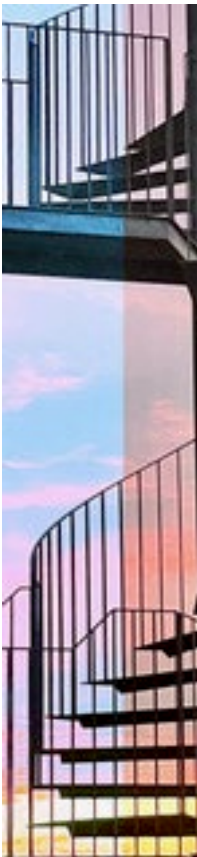


# ADDENDUM

Acknowledgment

Curriculum vitae

List of publications







## ACKNOWLEDGMENT

*This dissertation would not have been possible without the people who participated and actively engaged in its creation and the environments that motivated, nurtured, and supported its development.*

### PARTICIPATING PERSONS

To get this dissertation started, I experienced support from dear occupational therapy fellows; I am deeply thankful for **Astrid Kinébanian, Birgit Prodinge, Debbie Rudman, Ann Fischer, Anders Kottorp, Christina Schulze, Jenny Ziviani, and Sylvia Rodgers** – you all encouraged me in finding a path to earning a PhD, helped me develop my research topic, wrote recommendation letters, and connected me with others through your professional network. Your engagement was, for me, unexpectedly unconditional and generous. This PhD trajectory would not have been possible without the drive and energy of **Barbara Piškur**. Barbara, without even knowing me, you believed in me at a time when I did not believe in myself as a PhD student. With your seemingly endless enthusiasm, you searched for possible promoters at Maastricht University. You crossed interdisciplinary borders and persisted even after being rejected and having to start all over after a year of work.

Next, I want to express my warmest gratitude to my PhD team, which encouraged, pushed, and patiently accompanied my learning process with wisdom and high academic professionalism.

My profound gratitude goes to **Sandra Breuskens**, my promoter, for accepting me as a PhD student and acknowledging my desire to work scientifically. You motivated me to embark on a topic that truly addressed my clinical concerns. You were genuinely interested in my scientific and personal development throughout the project. Your free and creative mind fostered the establishment of more comprehensive solutions with practical impact during this process. In the moments I felt chaotic and overwhelmed, your respect and confidence in me to make wise decisions was an invaluable help. Thank you for letting me experience scientific freedom under your guidance and for acknowledging my struggles and learning processes.

**Albine Moser**, my daily supervisor, nurtured me with her profound scientific knowledge and guided me throughout this dissertation with her generosity and availability at every stage. Albine, you are a true educator – your comments were challenging in the right moments and supportive in the moments I felt blocked. Your diverse methodological knowledge challenged me in the planning of each study and forced me to rethink them repeatedly until they were profound enough to be sincerely scientific. Reflective discussions with you helped me to distill single artifacts into coherency. I admire your seemingly endless patience, as well as those rare moments when you lost it, which often allowed me sudden clarity and understanding. What a privilege to experience you as a daily supervisor.

I also owe my sincerest thanks to my third supervisor, **Barbra Piškur**, who constantly reminded me to pursue the perspective of parents of adolescents with ASD. Barbara, you brought a profound occupational therapy perspective into this dissertation and offered your huge personal network to connect me with other scientists, particularly those at CanChild. Being socialized within the German language, it was challenging for me to write in a structured and concise manner, as you demanded. I am deeply thankful that you focused on the user perspective for all publications. Because of your standards, they are readable and comprehensive.

I am also profoundly thankful for my co-authors, who spent their thoughts and time to accompany and work with me for the sake of this dissertation. **Christina Schulze**, you comforted and encouraged me all these years. Your unsolicited feedback was of a kind that keeps a scientist nourished in times of doubt. You generously shared your children-focused scientific expertise with me. For their collegiality, adventurousness, and scholarly devotion to collection, analysis, and writing, I thank my co-authors **Uta Jakobs**, **Ruth Amman**, **Jillian Boyd**, and **Thomas Morgenthaler**.

Many friends, colleagues, and strangers have engaged with me in elaborating on this research topic over the past few years. Sociologist **Andreas Bänziger**, you generously shared your competencies and supported this research by programming the survey and performing step-by-step statistical analysis with me. I admire your endless patience and never-ending curiosity. Thank you also to **Simon Renzler** for a short but efficient statistic counseling session, and to **Aline Burkart** for helping transcribe interviews and driving me around. **Andrea Weise**, what a gift to my life you have been

since we started the master's together. Reflecting with you at the various stages of my research process and clustering together the quotes and codes was so much fun. Thank you so much. Thanks also go to **Elsbeth Müller, Anne Daverio, Erika, Simon, and Ben Lang, Uta Fisher, Bill Wong, and Ilona Hippold** for supporting me intermittently as a sounding board.

Publishing and writing a dissertation would not have been possible without tenacious language magicians: I am enormously grateful to **Maggi Lucy Bell, Greg Babb, Jan Klerkx, Anika Haake, Rachel Treplicky, Jillian Boyd**, and the editors of the Cambridge Proofreading service. Publishing is a hard job. Without clear and flattering language, content cannot be transmitted. Also, thanks to **Tiny Wouters**, who made the beautiful layout of this dissertation.

I am also infinitely thankful for **the 140 participants of the four empirical studies**. Without your engagement, your willingness to share personal experiences, and your contribution of time and energy to receive explanations, fill in a lengthy survey, or provide photos and interviews, I could not have completed this research. Your research participation as adolescents on the autism spectrum, parents of a child or adolescent on the spectrum, or parents of a child with a disability, was incredibly generous. My research cannot necessarily provide you with more personal insight, yet it contributes to the hope that a public expression of your enacted experiences and conditions may promote a better understanding of the situation of adolescents with ASD overall.

## SUPPORTING ENVIRONMENTS

As in the case of adolescents with ASD, **staff and services** played an important environmental role for me in creating this dissertation. Living in a secure, profoundly calm, and well-organized Switzerland allowed me the space to work freely on this dissertation. Since 2007, I have been privileged to work part-time at the Zurich University of Applied Sciences, a university that encourages and stimulates the lifelong learning of its employees. By providing me with a five-month sabbatical, ZHAW indirectly supported this thesis. I received encouragement, attention, and flexibility from my superiors and colleagues from the very beginning. Special thanks to **Ursi Gubler, Uta Jakobs, Brigitte Gantschnig, and Christiane Mentrup** for your support. I also received valuable advice from the lawyer of ZHAW regarding ethical issues arising from cross-border research. I am thankful that the Cantonal Ethics Committee in

Switzerland oversees ethical procedures to prevent harm to persons without making the life of researchers inordinately tricky. Receiving a grant from **Ergo Stiftung** in Zürich was a wonderful sign that this research is meaningful and valuable.

Finally, I thank all **those organizations** that contacted persons on the autism spectrum and actively supported my recruitment efforts. A special thanks to «*autismus deutschschweiz*», «*autismusforum*», the “*Klinik für Kinder-und Jugendpsychiatrie und Psychotherapie*” in Zurich (specifically **Ronnie Gundelfinger** and **Bettina Jenny**), St. Gallen and Bern, regional autism groups in Wallis, Bern, Nordwestschweiz, foundations such as the “*Natalie Stiftung*” in Gümlingen and “*Stiftung Kind and Autismus*” in Urdorf (specifically **Elvira Wolgensinger**), **Matthias Huber**, and professional associations for occupational therapy, special needs teachers, and psychomotor and social work.

Regarding attitudinal environments, I expressly thank the **University of Maastricht** for accepting me as an external PhD student regardless of my professional path, age, nationality, and financial contributions. I always felt that scientific contributions were the only measure that counted for this institution—what a generous attitude.

Performing profound research is much easier in a **rich, informative environment**. Enjoying access to the Central Library in Zürich and online access to the library of ZHAW was of measureless help for this dissertation. I also want to thank the designer **Sandra Staub** for her valuable support in designing the title of the thesis.

I would be amiss not to mention the **physical environments and their respective locations** that nurtured my work by creating moments of concentration out of daily duties and functioning. Beside my beautiful home in Zurich, this was a place in the old city of Stockholm around a chestnut and a vivid coffee shop, the barrenness of the Danish Island Fanø, a welcoming home and paradise garden in Santiago de Chile (always combined with the raging Pacific coasts), the calm lakes of Minnesota and the stylish art nouveau home in Hull near Boston. Back to Switzerland, the tiny village of Vättis, where I felt embraced and humbled amidst the impressive mountains. The serenity of Montevideo and the eternal terrasse of Bruno and Marianna; the sweetness of Liguria, especially seen from a bright flat in Rapallo, and the olive house in Diano Marina; the fleeting beauty of Pula in Istria, experiences from a beautiful modern flat

drenched by sea breezes and echoing with gulls and daily swims. There were even some more....

Nudging and motivational environments were also provided by everybody interested in these dissertations. **Cécile Küng**, your sincere interest in my actual works nurtured me enormously. Collaborating researchers, such as **Christian Liesen** and **Heidrun Becker**, had a substantial motivational impact on me. Your drive was contagious! You motivated me to perform research that matters to society. Your conviction that systems can change made an enormous difference for me. Thank you for the confidence you expressed in my work.

Working for over 20 years with children and adolescents and their families in the community provided a profound source of motivation for this dissertation. I want to thank **all children and adolescents within the autism spectrum**, and particularly those with whom I had the privilege to work with and accompany as an occupational therapist during parts of their young lives. Your eagerness to learn, your profound curiosity in seeming sameness, and your often shy and cautious attitude supported my deep respect for you and helped me become more sensitive to your needs. I have never worked with another client group as surprising, deeply funny, and intensive. You have touched my heart.

I also owe **all parents of a child on the autism spectrum** my deep gratitude. Without insight into your daily struggles and hopes, this dissertation would not have been realized. As an occupational therapist and researcher, I had the privilege of learning volumes from parents. Their struggle with hindering environments, such as eligibility for service delivery, negative attitudes, and lack of institutional flexibility deeply touched me. My admiration goes to all those parents who try to fulfill their dreams of creating a caring and inspiring family life in which adolescents with ASD are individual members just as any others.

There was also a social environment that supported me during this dissertation. Firstly, I want to thank **all my colleagues from ZHAW**, from the institute of occupational therapy, and from all other health professions who were friendly with me in those times when my resilience wavered. I also want to thank my students, who challenged me, and particularly those who got inspired to work more in-depth within the area of

ASD. Special thanks also to my colleagues at Kindertherapie Stäfa, **Sonia Italiani, Friederike Häsele, Tirza Sarah Stark, Mieke Visscher, Marfried Winkler, Aline Burkart, and Rahel Meleri**: you supported and pampered me in the times I felt exhausted and frustrated. You always reminded me that being an excellent occupational therapist does not depend on being a good researcher – what a relief! A special thanks also to the first **Swiss Action for Happiness Group** members. Meeting with you guys, sharing narratives about our sources of happiness, and nurturing joy and meaningfulness in life had a true spillover effect on this dissertation.

Finally, and like the most crucial environment found in this dissertation, I always had the fortune to be surrounded by **individually dear friends and family** who supported me emotionally despite the shortage of time during these years of digging into research. Thanks to **Christina Schulze, Andrea Weise, Lukas Erne, Vesna Terselic, Dijana Mladenovic, Rolf Hammer, Mario Guerra, Berta Staedler, Esther Bengoechea, Marco Bianchi, Regina Hüttenreich, Melanie Neeke, Anne Daverio, France Wildberger** and **Sebastian Bachman**. You laughed with me and dried my tears; you shared your love of life with me and let me participate in yours without conditions.

**To my family**, I owe my deepest gratitude. Dearest **Papa**, without your model of grit, I would not have endured this passage. You never give up. Dearest **Mama**, your laughter and your acceptance have nourished me all my life. My brother **Armin**, special thanks for taking responsibility for our family during these times of pandemic and illness. Thanks to **my African family**, who always gave me the feeling of belonging.

Next and foremost, endless thanks to my daughter **Maïka Joy Nimi**, my doe eye, my Lucertolina, my magnolia blossom. You are the music of my life. During these years, you never complained that I was often absentminded and that you had to witness nearly endless struggles through the writing process. You cheered me up and encouraged me to be proud of myself. What a gift to have you beside me.

## CURRICULUM VITAE

Beate Krieger was born on May 18, 1963, in Stuttgart, Germany. After receiving her general qualification for university entrance in 1981, she initially earned a degree in occupational therapy from an occupational therapy college in 1985. Completing her tertiary-level education in 2017, Beate was awarded a Master of Science in Occupational Therapy by the Amsterdam University of Applied Sciences (Amsterdam, Netherlands) as part of a joint program of the University of Brighton (Eastbourne, UK), the University College Sjælland (Næstved, Denmark), and the Karolinska Institute (Stockholm, Sweden).

Since 1986, Beate has lived in Switzerland, where she first conducted clinical work with adults with spinal cord injuries, orthopedic and neurological issues, and hand injuries. In 1996, she joined the World Health Organization in Mostar (Bosnia-Herzegovina) as a rehabilitation counselor. After returning to Switzerland, she switched her professional focus to children and adolescents and worked with severely burned children and those with traumatic brain injury at the Children's Hospital in Zürich. Beate shifted her career focus in 1999 to the community. Since then, as the owner of a community-based occupational therapy practice, she has worked with developmentally challenged children, adolescents, and their families.

Compassionate about teaching, Beate was a guest lecturer at occupational therapy schools in Zürich and Lugano between 1986 and 2007. Since 2007, she has been a nominated lecturer at the Zürich University of Applied Sciences (ZHAW), teaching a broad range of topics from occupational theory to occupational therapy practice and research. Beate received ZHAW teaching awards in 2012 and 2016, and a 2014 prize for the best publication of the ZHAW's Department of Health.

As a member of the Swiss Association for Occupational Therapy, Beate served from 1990 to 1999 as co-editor of the journal *ergotherapie*. Between 1987 and 1997, she was an active member of the International Fellowship of Reconciliation, providing courses in non-violent conflict resolution and activism in Switzerland and abroad. In 2010, she became a member of *autismus deutschschweiz*, an organization for parents lobbying for people within the autism spectrum. Further, Beate regularly reviews international scientific articles for journals such as *Work*, the *Journal of Autism and Developmental Disorders* and *Autism*.

Beate lives with her family in Zürich, Switzerland. She loves reading, music, gardening, hiking, swimming, campaigning, and traveling.





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